



The Hidden Patient

A Caregiver, Her Mother, and the Dementia that Afflicts Them Both

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Prologue

On an otherwise uneventful morning in July 2012, all the Milwaukee news outlets report the disappearance of an elderly couple and their dog. Forty-three billboards project the image of a stout man and a dainty woman, his complexion ruddy, her smile prim.

The names of the missing, last seen driving home, are Douglas and Berna Levy. I know them as Grandpa and Grandma.

My father is at least partly to blame. The night before my grandparents make headlines, Grandpa tailed his car on the drive from their new retirement community to my uncle Todd's house. Dad encouraged him to navigate the return trip without a guide, reasoning that a ride sans chaperone would reassure Grandpa of his independence. (Grandma needed no such encouragement. She had voluntarily surrendered her own set of car keys last March.) It is this trip from which my grandparents fail to return.

The next day, two detectives search the missing persons' apartment, five television newscasters interview Dad about his parents' whereabouts, and 18 hours elapse without news of or from the vanished. Finally, Grandpa and Grandma park outside a popular eatery in town to ask for directions. The couple whose meal they interrupt recognizes them from their televised picture.

My parents and I recover our wandering ones — who have spent the night crisscrossing the metropolitan area — in poor shape. Grandma is bleeding from her right hand. (The dog scratched it when he became desperate for a grassy place to pee.) Grandpa, his pride wounded, is crying. The car's interior reeks of cigar fumes, sweat, and urine. My grandfather can't recall how he lost his bearings, nor can he justify his illogical way of recovering them.

My family can't return his car keys to him, nor can we deny the decline of the keen mind that once navigated sailboats by a sextant and the stars.

A few months after the crisis, doctors at the Mayo Clinic in Minnesota diagnose Grandpa with is most likely Alzheimer's Disease. In the meantime, I spend a summer helping my grandfather as I can while my uncle Todd, his primary caregiver, works temporarily in another state. I learn that caring for a loved one with dementia is like navigating a car from the shotgun seat, when the windshield on the right side is filthy to the point of opacity and the driver recalls, at most, one direction at any given moment. For three months, I try to wrestle the steering wheel away from its unreliable master.

When I slip out the side door in August, I continue to think of the road on which Grandpa and Todd, now reunited, are bound. The traffic is thick: more than 15 million Americans and their 4 million relatives with dementia are driving the same route. I decide to follow another parent and child, a pair much closer to their exit, so that I can see what might lie ahead for my own family.

By the time her mother, Ruth, rises at 7:30 a.m., Jacklyn M. is drinking her way through a second pot of coffee, which she takes with whole milk and sugar. She's already dispatched the two cockapoos, Zorro and Kiwi, to their morning constitutional in the backyard; fed the family parrot; collected the laundry; and hauled out the trash. Jackie's eyelashes are pale, her hair swept into a haphazard ponytail, her feet exposed in purple flip-flops as she assembles first her household, then her mother's wardrobe.

Ruth Gomes has yet to choose the panties she'll wear today. A few pairs are strewn across the bedspread in her room, calling for trans-generational consensus.

Three years ago, Jackie decided to move Ruth, who is 83 years old and suffers from dementia likely caused by Alzheimer's, into the basement of her Long Island home. Since then, their shared life has been as cyclical as the movie *50 First Dates*, the story of a smitten lady-killer courting an amnesiac woman who forgets him every morning after.

Early in the day, Jackie is a patient, if resolute, date. "You're going to do this now, cookie," she says, extending the mouthpiece of a nebulizer to Ruth's hand. As Ruth inhales, Jackie scours the basement bathroom. She flushes the toilet because she knows her mother fears the whirlpool in the bowl.

When Ruth has taken her final drag from the nebulizer, she pulls out her dresser drawers as if whatever is eluding her in one might have slipped into another. Jackie asks her what she's looking for, but the answer is garbled.

"Ok, you'll figure it out," Jackie says. She starts a circuit of climbing and descending the basement stairs — up to reload the laundry machines, down to check on Ruth's state of undress.

The door to Ruth's bedroom closes and reopens five minutes later to reveal its

slight occupant in a pair of brown sweatpants and a black bra. Without fat to give them contour, skin folds hang slack from her arms. Three drawers protrude from the dresser like jeering tongues.

Jackie enters. She pulls a white turtleneck over her mother's raised arms and her head, mummifying them briefly. Ruth's face reemerges, her mouth clenched. Jackie senses her discomfort and loosens the turtleneck collar with a gentle tug.

When Ruth sinks to her bed to pull on her socks, she pauses. She tilts her head back so that Jackie can sweep a compact makeup applicator with no cover-up across her wan, unblemished face. The applicator is followed by a brush with no blush.

Jackie has been indulging Ruth's fantasies for years now. When Ruth was still pretending to manage her own affairs in a two-family Victorian in Woodhaven, Queens, Jackie spent months denying the unsuitability of her mother's living arrangement. Only very gradually did she realize, on weekly cleaning visits, that Ruth could no longer write her own checks or feed herself properly. Unpaid bills and empty junk-food packages hid in the kitchen cabinets. The individually packaged homemade meals Jackie had brought her idled for days in the freezer. Written reminders that Ruth had addressed to herself littered the entire apartment.

"She was totally bugging, and I didn't realize it," Jackie admits.

Concerned, she visited a few Long Island assisted living homes. They were asking for about \$5000 a month in private-pay fees, which, in Jackie's opinion, was "just out of this world." (Factoring in the decline of Ruth's cognitive skills over the last few years, Jackie estimates that an appropriate facility would now charge up to \$8,000 a month for her care.) Ruth's minimal social security, \$870 a month, would not begin to cover the cost. Jackie considered applying for Medicaid assistance on her behalf and moving her into a state-run

assisted living home in Flushing, but the home required more independence of its residents than Ruth would be able to sustain. There were two more factors in Jackie's decision. Mother and daughter had comforted each other when Ruth's husband died and when her son left the country; they'd grown accustomed to supporting one another with limited finances. When her husband's substantial salary moved Jackie into the upper-class income bracket, why shouldn't Ruth benefit in some way?

Jackie brought Ruth in for a battery of tests at Glen Cove Hospital, where doctors delivered the formal diagnosis of dementia and checked her into rehabilitation for six weeks. While Ruth underwent respiratory and cognitive therapy, Jackie hired a contractor to renovate her basement into an apartment for her new boarder.

When Jackie's son, Aaron, and her husband, Ben, came to pack Ruth's belongings into a U-Haul truck, they saw her illusion of household order firsthand.

The demented elderly pretend because, as Jackie explains, "It's a survival skill to show that they're doing fine — but they're not, and eventually they can't hide it anymore." Uncovered in Ruth's apartment: an empty paper cup swaddled for warmth in a drawer, Sweet'n Low packets shoved in niches, and thirty years worth of dust and grime concealed by the appliances. As Aaron and Ben worked, they overheard the landlord celebrating Ruth's departure. She had harbored the delusion that he frequently broke into her apartment at night to paint the walls; she had probably pestered him with complaints he had never reported back to Jackie. He now considered Ruth unwelcome in his house.

Where had she wanted to live, if not on her own? She couldn't tell you today, because she can barely string sentences together anymore, but studies have found that most aging parents do not want to burden their children by sharing their households. Before Jackie retired

her mother's Oldsmobile (Ruth had caused a few parking-lot fender benders by accidentally taking off in reverse), she had preferred to run local errands by herself.

Of Jackie's decision to accommodate Ruth and her needs full time, Jackie's friend Eleanore T. says, "I think she was well aware of what she was going to step into." Jackie had quit her job as a physician assistant for a respiratory specialist a few months earlier (a decision she made before her mother's diagnosis), so she could cite three distinct advantages over other caregiving daughters: more medical expertise, more time in her days, and more financial support from her husband than the average woman.

"Of course," Eleanor continues, "you never really know the whole story until you're actually living it."

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Nearly 3.8 million Americans are living with dementia, according to a RAND corporation study, the most rigorous of its kind to date, published this April by *The New England Journal of Medicine*. By 2040, as mortality rates decline and baby boomers enter their later years, that number will swell to 9.1 million. The U.S. population age 85 and over is set to quadruple from 1999 to 2040, a telling predictor for the incidence of Alzheimer's Disease; close to half of all people age 85 and older have it.

As the number of afflicted people balloons, so will the price of caring for them — from \$200 billion this year to as high as \$1.2 trillion in 2050. Medicaid, a program that finances the medical needs of low-income American families, may be paying most of the bills for long-term supports and services (LTSS) in this country, \$97 billion worth, but it's family caregivers who form the foundation of long-term care. Their contributions, financial and otherwise, become ever more crucial as the direct care workforce shrinks, as healthcare consumers insist that

caregivers belong as partners on teams of patients and clinicians, and as the government shifts long-term services away from institutional settings to those in the home and the community so as to please patients and save money. Medicaid dollars, on average, can support nearly three dementia patients in home and community-based settings for every patient in a nursing home.

In 2011, the AARP Public Policy Institute calculated the family caregiver's hypothetical hourly wage at the state level as \$11.16 (a weighted average of the state minimum wage and the median hourly wage of a home health aide). The institute determined that 42.1 million family caregivers in the U.S., spending an average of 18.4 hours weekly to care for relatives older than 18, saved the nation's health care and LTSS about \$450 billion in 2009, up from \$200 billion in 1996.

A recent analysis of family caregiving and LTSS over 20 years found that until the mid-1990s, families usually hired paid help. These days, more family caregivers are carrying the load alone, because developments in health care, including expanded homecare technology, have made the home a better hospice, and the recessive economy has made the visiting nurse a more expensive commodity.

Yet even as the needs for and of family caregivers intensify, their numbers dwindle. In 1990, there were 11 informal caregivers for every older care recipient. By 2030, the ratio will be six to one: with fertility rates falling, there will be fewer children to care for the baby boomer generation; more women, who have traditionally assumed the onus of caregiving, are working full time; and as caregivers shoulder more of the emotional, financial, and physical burdens their role entails, they begin to buckle under pressure. In 2010, they found no relief from the 31 states that cut non-Medicaid aging and disability services programs.

The irreducible truth of a life like Jackie's is that, as Matt Kudish, Vice President of the

Alzheimer's Association's New York City chapter, put it, "No one can care for someone with dementia alone." It takes a nation to nurse the aging.

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"Maybe I should have..." Ruth begins a sentence with no audience, dragging a black comb up the back of her head. She pats her teased hair into place as the comb advances.

Ruth has apraxia, a disorder that impairs her speaking ability. As John Bayley observed of his wife's condition in the memoir *Elegy for Iris*, "An Alzheimer's sufferer begins many sentences, usually with an anxious, repetitive query, but they remain unfinished, the want unexpressed." If Jackie were nearby, she would coax meaning from Ruth's words.

"I speak her language," she explains. "It's like a mother who can understand her kid when they're babbling. Your mother knew what you wanted. No one else did." In what seems like an unconscious recognition of their role reversal, Ruth often mistakes Jackie for her own mom.

Fluffing her strawberry blonde coiffure with a round brush, Ruth stares at the mirror above her bedroom dresser. It's unclear whether she sees anything besides her hair: the drooping eyelids, the striations in her cheeks, the age spot on her right temple. Ruth's preening ritual is an automatic one, stripped of intention the way hair is stripped of its natural color by bleach.

Jackie watches Ruth fetch her Suave Touchable Finish hairspray and spritz her left hand in the purgatorial room that is neither corridor nor parlor. A fruity chemical scent dissipates as she fingers her curls.

"It's beautiful," says Jackie, whose hair is still a wild nest, of Ruth's shellacked

'do. Ruth chuckles modestly. Jackie suspects her mother's asthma is caused in part by her liberal use of hairspray — never mind her years of heavy smoking.

She climbs the stairs, expecting Ruth to follow at her own pace. Ruth mounts them slowly but independently, her body pressing forward, her consciousness lingering behind.

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Ruth grew up in Corona, Queens, one of the eight Basile children. They pronounced their Italian surname like the herb, lopping off its final syllable. Their father, Matthew, worked through the Depression welding metal beds, and their mother, Nancy, was a homemaker who put her kids to task around the house. There was never much money to spare in the Basile household, says Barbara Deeks, the second oldest sibling.

Ruthie, as Barbara calls her sister, stood 5 foot 2 and weighed 100 pounds. A lightweight, but a spunky one. “If she wanted to fight, she'd fight; if she wanted to be fresh, she'd be fresh,” Barbara says. Ruthie was probably closest to her ailing sister Marion, crippled by arthritis from an early age, but she spent her Friday and Saturday nights with Barbara at the Queens Roller Rink in Elmhurst, where the girls skated to organ music and Barbara met her husband.

Where Ruthie met her own husband, Thomas Gomes, remains a family mystery: Jackie has somehow misremembered Barbara's charming story as Ruth's, but Ruth has never told Barbara how her courtship with Thomas began.

Barbara *does* know he worked at his family's amusement park in the Bronx, then at his father's bar, and finally in construction. Ruth, a frugal clotheshorse who emulated Jackie O's classic style with her bargain purchases, found brief employment in the stationery department at the chichi Cartier retail store on Fifth Avenue. She even lent her petite hands to a print

campaign in magazines and newspapers advertising the company's delicate watches. When she became Mrs. Gomes, she started to clerk at a bank in Jackson Heights.

Before Thomas drank himself to death at the age of 47, he and Ruth had two children and raised them as Roman Catholics. Thomas's namesake would grow up to paint abstract canvases and shoot heroin. His sister describes him as "a total fuck up," or the family's Keith Richards. After he emigrated to Spain in 1982, Ruth heard little more from him than messages in the occasional card, but she continued to speak adoringly of her only son.

And then there was Jackie. Ruth often gave her daughter more freedom than was good for her. "She was so busy dealing with my father's shit and my brother's shit, I was kind of just left alone to my own means, so I pretty much grew up quick," Jackie says. "I was the one smoking cigarettes in the parking lot. I was the one cutting out." When Jackie ditched classes at her parochial school, she went off to experiment with Quaaludes and party at Studio 54 with Andy Warhol and Debbie Harry. Without hesitation, Jackie narrated these exploits to her mother. Ruth may have been a good listener, but she was also a conservative housewife, judgmental of her daughter's rebelliousness and concerned with what the neighbors might think. (She especially disapproved of Jackie sleeping with boys before she was married). She and her daughter quarreled constantly, about matters so immaterial to Jackie now that she struggles to recall any one in particular.

After Thomas Sr.'s death in 1977, Ruth began to panic about her family's financial stability. Dutifully, Jackie started taking up odd jobs, including a stint of her own at Cartier's, at 16, just as the Gomeses minus one moved to Woodhaven. She would support herself and Ruth with a bachelor's degree in nursing from Hunter College until she took out a student loan to become a physician assistant, one rank below an M.D.

Even after Jackie married Behnam M., an Iranian accountant, and moved into a two-bedroom condo in Forest Hills, she never neglected her mother.

Eventually, Jackie and Ben would put down roots on Long Island, in a manicured neighborhood Jackie couldn't have imagined while growing up in the tenements of Corona. Ruth visited Jackie, Ben, and their two children, Gabriela and Aaron, on the weekends. She favored Aaron, taking him out to the local deli, driving him to his karate lessons, and teaching him to play baseball and basketball. A picture of the grinning pair in Jackie's basement shows a cherub-cheeked boy and his ample grandma, proud of the grandson who might somehow make up for Toms one and two.

Ruth gained the weight after Jackie, herself an on-again, off-again smoker, convinced her to quit. Ruth had endured years of respiratory tract infections before doctors diagnosed her with chronic obstructive pulmonary disease at age 61. The solution to Ruth's nicotine addiction, Jackie believed, was Dr. Wong, an ancient acupuncturist who spoke little English. Outside Dr. Wong's office, Ruth sat smoking in Jackie's car as she warned her daughter, "You're wasting your money — this is a bunch of bullshit." In they went anyway. Jackie paid \$340 for one session of needling. Ruth never smoked another cigarette.

"Ma, do you miss smoking?" Jackie once asked Ruth.

"Yeah," she said.

That answer would have made good sense if she hadn't given exactly the same one, in exactly the same way, when Jackie asked if she missed peanut butter, which she eats at least once a week. Ruth understood Jackie's interrogative tone of voice, but not her words.

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Ruth's hand quivers as it delivers spoonfuls of Greek yogurt to her mouth. It pauses momentarily, poised over a Charlie Brown mug as if the coffee steaming inside were soup. With a sip from the mug, Ruth swallows the two little pills — one pink, one magenta — that Jackie has set on her violet placemat.

Outside, airplanes rumble as they soar by; overhead, the ceiling creaks with the footsteps of Ben and Gabriela. Both work for Vasomedical Inc., a medical technology company, Ben as an accountant, Gabby as an employee in the marketing department. They pass through the kitchen before they leave for the day, directing their goodbyes only to Jackie.

Ruth finishes her breakfast and prepares herself for what she thinks of as “work,” the adult day program at which she spends four days a week, five hours a day. She shuffles to the sitting room in the front of the house, where she sits in a chair facing the room's bay window and the empty cul-de-sac of C. Drive. As usual, she has no idea what the time is now (8:58 a.m.) and no idea what time her bus normally arrives (9:30 a.m.).

Zorro the cockapoo, wearing a red sweater and a dolorous face, comes to rest at Ruth's feet. She leans forward to pet his head.

“You're cold,” she says and instructs him to give her a kiss, puckering her lips, and bending further forward. He stands on his hind legs to meet her halfway, his front paws on her shins.

Zorro never looks at Ruth with anything but affection — and a desire for hers. Studies have shown that pets offer unconditional positive attention to dementia patients who struggle with verbal communication, reducing the frequency of their mood swings. Zorro and Kiwi never recoil from the dramatic faces that Ruth makes in distress, faces that frighten Gabby, perplex Ben, and find their interpreter in Jackie. Jackie has names for each of them: the

“furious face”; the “shower face”; the “frustration face” that makes her look as if she’s just been hit in the head; the “deer-in-the-headlights face” that appears when she can’t grasp Jackie’s instructions.

Jackie joins Ruth in the sitting room, which is silent except for the distant rattle of the washing machine. Ruth has sheathed her hands between her legs, and her eyes strain as she stares through the window, crow’s feet collecting at their outer corners. Seated farther from the front window, Jackie rests her head on her right hand and pockets her left between her thighs, as if to contain its restless energy. She hopes that Julius, the bus driver, will arrive promptly, so she can send Ruth on her way, hop in the shower, and get to her doctors’ appointments.

Ruth begins to rifle through her Le Sport Sac purse, searching for the lipstick she has yet to apply. Her fingers find an inhaler with which she tries to paint her lips — until she recognizes the feel of plastic. She takes a puff from it instead.

“You have the urge to jump in and just do it for her,” Jackie says, “but you don’t, because it keeps her busy.”

Ruth rummages through her bag again, her eyes narrowed, her end elusive.

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When German psychiatrist Alois Alzheimer first described the symptoms of his namesake disease in 1907, Americans considered dementia in old age an inevitable sign of “senility,” or decline in one’s later years. Thirty-three years earlier, American neurologist George Miller Beard had described mental deterioration as the disaster that inaugurated death’s vegetative process: “Men die as trees die, slowly and frequently at the top first.”

In 1909, Ignatz Leo Nascher, a sensitive medical student working at a New York hospital for the destitute, could not understand why his preceptor ignored an old woman's insistent demands for attention. Nascher, whose work founded the field of geriatrics, realized that physicians disregarded the voices of the old because they didn't know how to listen to them. He strove but failed to distinguish clinically between what he termed "normal senile degeneration" and a pathological "softening" of the brain.

In the aftermath of World War II, the first gerontologists — American scientists, policy makers, activists, and entrepreneurs — devoted themselves to hearing the elderly's concerns. Yale anthropologist Leo Simmons argued that "senility" was a status modern society ascribed to members it considered useless, rather than an objectively measurable state of physical weakness or psychological infirmity. He pointed out that not every old person was as mentally incapacitated as a patient like Ruth; the young simply did not value their elders' wisdom as they once had.

The experience of aging in the United States changed dramatically in the 1960s, as older Americans organized for political and social change on their own behalf in advocacy groups like the American Association of Retired Persons. They spoke up against "ageism," a concept that gerontologist Robert Butler coined in 1968 to describe the "systematic stereotyping of and discrimination against people because they are old." Elderly Americans rejected the ageist idea that the old inevitably experience physical and mental decline.

The word "senility," Butler insisted, had to go. It wasn't a specific medical diagnosis, but rather a wastebasket term applied to any retiree with a health complaint. It was a term that rationalized the neglect of such complaints by assuming they were inescapable and irreversible,

instead of considering the possibility, as was sometimes the case, that they were manifestations of anxiety and depression.

Butler would begin to deconstruct the broad concept of senility as the first director of the National Institute on Aging, established in 1974. He made funding Alzheimer's Disease research an institutional priority, because the best way to attack the loathed term "senility" was to support the development of diagnostic procedures that could discern the difference between the irreversible dementia of Alzheimer's and the reversible dementias caused by treatable conditions. The clinical neurologists and biochemists enlisted in the fight in the 1960s and '70s maintained that Alzheimer's was not a normal part of aging, but a disease whose mechanisms could be unraveled and one day treated through research.

But is the label "Alzheimer's" really any better than "senility?" Alzheimer's Disease is known to damage the cognitive skills one needs to maintain an inner sense of selfhood and to present a coherent self to others. Representations of Alzheimer's sufferers in the popular culture depict them as ghosts or loose cannons who have lost their status as stable, respected, middle-class citizens. The Crazy Cat Lady, for example, who occasionally appears on an episode of *The Simpsons* screaming gibberish and throwing cats, once earned a Yale law degree and a Harvard medical degree according to the animated show's creators. The promotional copy on the back cover of one paperback on Alzheimer's reads: "They shoplift. They're violent. They 'expose' themselves in public. They're verbally abusive. They lie. And they don't know any better. Meet some of the 4 million Americans who have Alzheimer's Disease in the pages of 'The Living Death.'"

If that paperback gets anything right, it's that Alzheimer's is a condition of death-in-life and life-in-death.

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A short white school bus pulls up into the driveway. Relieved, Jackie dresses Ruth in her outdoor clothes — a purple down jacket and green cashmere scarf — with the same determination that it takes the mom to stuff Randy into his puffy snowsuit in *A Christmas Story*. Jackie steers Ruth through the garage and into the hands of the adult day care aide. Alberta Oliver braces Ruth from behind as she climbs the bus steps and then buckles her into the right-hand side of the second row, next to the window.

As the bus takes off, the heater at Ruth's feet blasts hot air, roasting her shins. Her gloveless hands remain cold, hidden turtle-like in her sleeves.

"I should have worn a hat," she mutters. Her voice is raspy, as if she hasn't inhaled enough air. A fake-fur-trimmed hood is attached to her jacket, but she has either forgotten it or decided she doesn't wish to flatten her hairdo.

At most stops, passengers board the bus on the arms of their home health care aides. The only man to arrive by himself wears a snakeskin cap and welcomes Alberta's assistance when she buckles him into his place. "I give up!" he cries roguishly.

Once the troupe is assembled, the bus arrives at the Glen Cove Day Program, where Melanie Raymundo, the peppy recreation coordinator, welcomes everyone and asks about their mornings. She guides Ruth into the main room, pulling out a chair to seat her between an old man and an old woman at a long table covered in a paisley-patterned cloth.

Throughout the morning conversation and puzzle-solving session, Ruth giggles politely at jokes that almost certainly escape her understanding, but her smile is authentic. She thanks the program employees for escorting her — they do so delicately, equating her small size with fragility — into the exercise room for chairbics.

When the routine begins, Ruth struggles to follow the instructor's verbal cues, and she doesn't know whether to mirror Sharon's actions or replicate them exactly. The barbells in her hands weigh only a pound, but, judging from the strain of her arms, they might as well weigh twenty pounds each. She perseveres, trying to lift her arms all the way up, but capable only of shrugging. A stereo plays in the background, pumping out the Bee Gees' "Stayin' Alive."

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When the U.S. government enacted Medicaid and Medicare as an amendment to the Social Security Act in 1965, it made public insurance payments for privately operated health services the rule in this country. The new law stipulated that states' Medicaid plans, describing the scope and nature of their programs, be subject to the review of the federal Health Care Financing Administration (what is today known as the Centers for Medicare and Medicaid Services). States were guaranteed federal money if they offered their residents nursing home care; they could, but did not have to, provide community-based care services.

"The thinking way back then was that if somebody needed total care, they needed it in some kind of institutional setting," says Richard Fortinsky, an expert on gerontological policy at the University of Connecticut's Center on Aging. After 1965, the nursing home industry grew rapidly, establishing powerful lobbying organizations and a national bias toward institutional care that persists to this day, despite financial evidence to the contrary.

Nearly three out of every four Medicaid dollars, jointly subsidized by federal and state governments, go to the costs of nursing home care, rather than the expenses of the full-time custodial care that professionals and family members administer at home. On a per-person basis, nursing home services prove more costly: in 2005, Medicaid spent an average of \$26,096 for each person receiving services in a nursing facility, compared with an average of \$9,459 for

each beneficiary of home and community-based services.

Families who choose to care for loved ones with chronic conditions like Alzheimer's at home find that Medicare dollars, which pay for the "skilled" care of Americans with disabilities and Americans age 65 and older, are just as unhelpful: Medicare covers only acute medical services necessary for a few weeks after hospitalization, not continuing custodial care. In 2011, the program paid for only 28 percent of the long-term care needs of older and disabled Americans.

The U.S. government is not entirely indifferent to beneficiaries' preferences: in 1981, Congress authorized waiver programs for individuals who fiscally and physically qualified for Medicaid but wanted community-based services. Nowadays, every state Medicaid program offers federal waivers for transportation, personal care, homemaking, adult day care, and case management services.

But the basic facts of paying for long-term care haven't changed. The financial responsibility still falls largely on the individuals who need care services and their families. Medicaid pays for care assistance only after beneficiaries have spent down their assets to \$20,000 or less. And those aging Americans who *can* afford long-term care insurance to fund their late-life needs often discover that their expenses surpass insurance premiums and coverage limits.

To those Alzheimer's patients and their families who find themselves overwhelmed by the task of planning for the future, organizations like the Alzheimer's Association can offer guidance. Established in 1979, the voluntary health non-profit runs a 24-hour hotline that answers caregivers' questions, as well as a care consultation program that provides individual and family counseling. "We meet the client where they're at," says Matt Kudish, the care

consultant program coordinator. “We don’t try to fit everybody into a box.” Consultants may help caregivers develop a care plan, negotiate the plan with their siblings, navigate the nursing home system, or fill out Medicaid paperwork. The association also arranges workshops that educate families about and prepare them for the legal and financial repercussions of Alzheimer’s.

But sometimes, Kudish says, all families want is “a reassuring voice and an ear of somebody who understands what it is that they’re going through and who can just say, ‘Yeah, that sounds really tough.’” Kudish believes that caregiver support groups serve as emotional “lifelines” for caregivers who feel isolated by their responsibilities. Many adult day service centers, like Ruth’s, hold support group meetings where caregivers can commiserate and share their coping strategies. In Fortinsky’s opinion, “Caregiver support groups *do* provide adequate emotional support for those caregivers who find value in group therapy.” But the truth is that not everyone likes to wear her heart on her sleeve.

Jackie attended a support session at Glen Cove Hospital, where she learned one useful trick: keeping her mother busy by giving her towels to fold. She hasn’t gone back because she says she doesn’t want to hear the “bullshit,” or other caregivers’ feelings.

“Unless they’re offering me a prescription and a bottle, it’s not doing nothing for me,” she says, somewhat jokingly.

Jackie may see no point in group therapy, but she praises Ruth’s recreational adult day program as “the best thing on earth” and extols its employees as “miracle workers.” Adult day service centers date back to 1973, when the national Administration on Aging started allocating funds to local non-profits. States assigned these non-profits, Area Agencies on Aging, to the tasks of coordinating and implementing services for older adults who preferred to

continue living in their communities. By now, these agencies have founded more than 5,000 adult day service centers in America, offering safe, interactive environments for participants and respite for their caregivers. The private-pay daily rate for such centers averaged a relatively affordable \$65 in 2013. The suggested daily contribution at Glen Cove, which is funded by national, state, county, and city governments, and which offers as many as 17 participants full supervision every weekday from 10 a.m. to 3 p.m., is \$40.

“Adult day in many instances eliminates the need for ever having to go to a nursing home,” program director Lisa Craig says, with pride. “And it’s much, much less costly.” If it weren’t for the five hours a day four days a week her mother spends at the program, going on two years now, Jackie says she couldn’t have managed Ruth’s care as long as she has.

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At noon, Ruth sits at a round table and eats lunch with Eva and Concetta, two other adult day program participants. Throughout the three courses of their meal, Ruth and Concetta whisper to one another, giggling now and then like schoolgirls. If Concetta finds Ruth’s words unintelligible, as most people do, her wart-speckled face masks her confusion.

Ruth dines with passable manners and a hearty appetite. She alternates tiny bites of sauerbraten with sizeable bites of potato. Her cheeks ripple when she chews. With the red cabbage, red potatoes, and brown meat on her plate, she makes a messy collage that she then consumes in its entirety. She is the only one at the table to finish her food, and she tells Alberta — who has been lunching at the next table with the other aides and discovers Ruth’s empty dish with surprise — that she hasn’t eaten since last week.

Ruth extends her chapped hands to Concetta, complaining of pain.

“Did something bite you?” Alberta asks, teasing.

“You did,” Ruth says. With affection, Alberta cups her right hand over Ruth’s.

“Your hands are so cold,” she notes. “Why are they so cold?”

“I’m dead.” Ruth delivers her answer deadpan, as Alberta’s jaw drops in astonishment and Concetta chants in Italian: “*Che fresca è innamorata, che calda è malate,*” or “That which is cold is in love, that which is hot is sick.” She breaks out singing an Italian folk song. Alberta just laughs.

When Ruth’s words started slipping away from her in her sixties, she knew she was losing her memory. Seven years ago, she forgot how to say her Hail Marys, so Gabby printed them out for her. As recently as six months ago, she was still self-aware enough to tell Jackie, “I can’t get my head straight.” Disturbed, she would blame her hazy thinking on her medication. Jackie reports that nowadays Ruth appears oblivious to her own plight.

And yet, in this strange moment, Ruth’s words hint at a tormented inner monologue. In a *New York Magazine* article about his own demented mother, Michael Wolff reflects that it may be wrong to think of dementia as an absence or a non-state. “It actually could be a condition of more rather than less feeling,” he writes, “one that, with its lack of clarity and logic, must be a kind of constant nightmare.” Death at least guarantees the dementia patient an end to bad dreams.

“We pass the time while we’re here,” Concetta tells Alberta, perhaps as a justification for her silliness. Ruth wipes down their table, playing the housewife out of habit.

“Come on,” she says, reaching out a hand that steadies Concetta as the Italian woman begins to warble, “I Want to Hold Your Hand.” Melanie watches the two begin their precarious walk to the long, paisley-patterned table.

While the “wobbly lead the wobbly,” as Melanie puts it, Jackie is at the gynecologist’s

office, getting her cervix dilated and her uterus flushed. A year and a half ago, she underwent a procedure to remove the muscular tumors that had been growing in her uterine lining; she's been plagued by searing abdominal pain several times a month ever since.

Jackie's and Ruth's bodies have both turned against them, but there is at least a remedy for Jackie's reproductive system, no matter how distasteful the prospect of a hysterectomy may be. There's no such fix for Ruth's brain.

*

Ruth has her good days and her bad days. On the good ones, she is calm and smiley; she gives compliments and she remembers that she's been living with Jackie for three years. On the bad ones, she can be frantic, accusatory, clumsy; she may ask the time of day over and over again, or accuse Aaron of impregnating a woman at the day program, or defecate all over the bathroom.

Ruth's ability to function normally varies so extremely because Alzheimer's has depleted her cognitive reserve. Cognitive reserve is the brain's back-up tank, or spare functional capacity, in times of stress. It allows humans to go about their tasks of everyday living even when they haven't slept well the night before or when they feel nervous about an impending deadline. Alzheimer's diminishes the brain's back-up power as the disease kills nerve cells. When stressors like a bad night's sleep affect Alzheimer's sufferers, they have to scrape the bottom of their reserve to remember basic skills, like brushing their teeth or putting on their clothes. If they reach deeper, to hold a normal conversation for example, they come up empty.

In the brain afflicted by Alzheimer's, the cortex shrivels up, damaging areas involved in thinking, planning, and remembering. The hippocampus, an area of the cortex that plays a

central role in the formation of new memories, shrinks first and most. Plaques, or clusters of a sticky protein called beta amyloid, build up between brain cells. Scientists have recently proven their hypothesis that the plaques block cell-to-cell signaling and trigger an immune system reaction that devours disabled neurons. Tangles, or once-straight molecules called tau proteins that have collapsed into twisted strands, destroy cells' vital transport systems, depriving them of the nutrients they need to survive.

The symptoms of an Alzheimer's sufferer develop so gradually that they're easiest to catalogue in retrospect. As plaques and tangles multiply throughout her brain's cortex, an Alzheimer's patient will struggle to remember the past, express herself in words, reason abstractly, process visual and aural stimuli, and manage the activities of daily living. She may get lost easily, show poor judgment, and become depressed or prone to outbursts of anger.

When doctors diagnose Alzheimer's disease, they rely chiefly on documenting such symptoms, as well as overall mental decline, with brain-imaging technologies, neurological exams, and mental status tests. Only post-mortem autopsies, which reveal the disease's trademark plaques and tangles in what look like desiccated brains, can conclusively verify their hypotheses.

But the diagnostic paradigm is shifting. Research has proven that the pathologic changes in the brain characteristic of Alzheimer's develop and cause measurable brain damage years before affected individuals meet the criteria for mental decline. Neurologists are working to develop tests that will enable the early detection and treatment of Alzheimer's. So far, the most auspicious advances are molecular imaging technologies that highlight deposits of beta amyloid proteins in the brain, and analyses of spinal-tapped cerebrospinal fluid for beta-amyloid and tau proteins. Just last year, the FDA approved for clinical use a radioactive tracer

that binds to amyloid and makes its nuclear imaging possible.

To skeptics who question the point of diagnosing Alzheimer's when its treatment is still elusive, William Hu, a cognitive neurologist at the Emory University School of Medicine, says the only way to test some of the new preventive treatments is "to know who actually has the disease, instead of just blindly treating people with any type of memory trouble."

The Alzheimer's drugs currently on the market can improve cognitive function and slow mental deterioration, but only temporarily. One class of medications prevents the breakdown of acetylcholine, a neurotransmitter deficient in Alzheimer's sufferers that sends messages between brain cells. The best known of these meds, Aricept, boosts memory performance for a year, but when that year is up, mental degeneration continues.

The cutting edge of research promises treatments that will prevent, rather than postpone, the onset of Alzheimer's. Pharmacologists are testing a new class of drugs that prevent beta amyloid from accumulating in the brain. Such drugs include compounds that block enzymes generating the protein, and vaccinations that spur patients' immune systems to make anti-amyloid antibodies. Although Hu admits recent therapeutic trials haven't had great success, he insists that progress has been made.

Progress takes money, and, according to the editors of the Alzheimer's Forum, an online scientific community dedicated to understanding the disease, 2012 was a "dismal year for funding." In February 2012, the Obama administration announced it would invest an additional \$130 million in Alzheimer's research over the next two years — a small sum compared to the \$2 billion that advocates had called for.

In the meantime, fear of Alzheimer's disease has come to plague most older Americans, says Dr. Richard Lipton, the principal investigator of the Einstein Aging Study. Every time

Jackie forgets a name in the course of telling an anecdote, she worries that she has begun to follow Ruth's downward spiral.

*

When the short white school bus finally turns into the driveway on the cul-de-sac, Jackie emerges from the garage wearing black mascara, a black caftan top, black corduroy leggings, black socks, and no shoes.

"Did you have a good day today?" she asks Ruth, steering her into the house.

"They said they're going to make it colder tomorrow," Ruth answers as Jackie begins to peel off Ruth's outer layers.

"Who said?" Jackie prompts her, but the mystery of the pronoun goes unresolved. Ruth, now molted, has begun her descent into the basement.

When she reappears, she sits at the kitchen table to eat the snack — a cup of applesauce, a cup of black tea, and an anti-psychotic pill — that Jackie has prepared her. Jackie excuses herself. "I just got to sit down a minute. I got a cramp," she says, overcome with the abdominal pain her earlier procedures failed to alleviate. She walks into the living room and sprawls on a cushy armchair, Zorro inviting himself to join her.

When Jackie recovers, she fetches a laundry basket full of clothes and instructs Ruth to fold them because the task keeps her calm and busy. While Ruth competently handles the shirts and towels, tucking them neatly back into the basket, Jackie prepares a salad of mixed greens, Parmesan cheese, and pine nuts.

After all the clothes are folded, Jackie summons Ruth to dinner.

"Hey Aaron, do you want to eat now?" Jackie yells down the basement stairs. In the silence that follows, Jackie whispers a conspiratorial "no" to Ruth, who is already seated

before her food — a small plate of gemelli pasta and tomato sauce, an oven-baked roll, and a half-glass of V8. She laughs in cahoots. Aaron has been sulking in the basement all afternoon, disheartened by the prospect of starting his spring semester at Stonybrook next week and by the recent breakup with his girlfriend.

As they finish their meal, Ruth notes how dark it's become outside. The backyard is virtually invisible through the kitchen windows, but the fence on the perimeter of the grounds can still be seen, faintly.

"Yeah, it *is* dark," Jackie agrees. "We don't like the dark. But soon it's going to be light," she says, thinking of late sunsets in the warmer months.

"Now?"

"No, not now. It's winter." Jackie's answer will not reach Ruth, who goes to the living room to watch, and misunderstand, a talk show called *The Doctors*.

Jackie serves her a bowl of homemade jasmine rice pudding, eats a helping herself, and then escapes into the darkness outside for a smoke. She reappears minutes later with her mother's eye drops in hand, administers them abruptly, and asks Ruth if she's tired.

"Yeah."

"I know you are," Jackie says, consolingly. She knows what tired feels like.

*

For all the time and effort that modern medicine has dedicated to extending American lives, it has given little thought to their quality.

Longevity exacts a price: now that Americans aren't dying from acute or infectious diseases, they're living their later years with chronic illnesses and the accompanying disabilities — in other words, in anything but good health. In the opinion of Michael Wolff,

the *New York Magazine* writer, this late-life existence is “not just a drawn-out, stoic, and heroic long good-bye.” It’s “human carnage.” As technology delays the death of the old, it increasingly drafts the young for “indentured servitude,” as Wolff provocatively calls the act of caregiving.

Whether or not caregiving amounts to servitude, it *is* hard. Caregivers may endure stress, frequent sleep disturbances, financial hardship, and social isolation; they become what sociologists call “hidden patients” who need support and care to address the negative impact their relatives’ illness has on them.

Over the last three years, Jackie says she has gained 25 pounds and aged 30 years. Before Ruth’s doctor upped the dosage of her anti-anxiety medication, to quell her flights of rage and help her sleep until morning, Jackie rarely got a night of uninterrupted sleep. Her social circle has dwindled to a few girlfriends who respect the fact that she can give them limited attention.

Research has shown that the closer the relationship between the caregiver and the care recipient before the onset of illness, the more distressing the caregiving role is. Caregivers are likely to become depressed and anxious, to feel resentful and angry at times, guilty at others. Jackie says she always feels stressed, either out of pity or of frustration. “If Mom wets herself and she’s trying to hide it, like a kid, I feel so bad when that happens,” Jackie says. “And then there are times when I just want to push her out the door.” Some caregivers have even felt that their sacrifices entitle them to siphon money from their charges’ accounts.

The impact of caregiving is not only emotional but physiological: a 2007 study of the DNA of family caregivers of people with Alzheimer’s showed that their telomeres — the ends of their chromosomes — had degraded enough to indicate a four-to-eight year shortening of

their lifespans.

But Yale assistant professor of epidemiology Joan Monin, who led a recent study evaluating how Alzheimer's patients and their caregiving spouses maintain feelings of security as they struggle with the illness, says it's counterproductive simply to conclude that caregiving, which is essential to American society, is bad for you. Monin says the way to begin supporting caregivers is by determining which stressful circumstances they experience most acutely.

Gerontological expert Richard Fortinsky reports that momentum is finally building to develop a standardized assessment tool that will evaluate how families caring for their relatives are coping, particularly how close they are to admitting their loved ones to nursing homes.

In the future, Fortinsky would like to see a partnership arise between health care professionals and community resources for the elderly. Home-care workers, he says, do not have enough training in the custodial care of patients with dementia. And the average family doctor diagnosing an Alzheimer's patient doesn't refer her family members to their local Agency on Aging or Alzheimer's Association chapter because he hasn't heard of them.

This organizational gap is what the Affordable Care Act, signed into law in 2010, aims to bridge. The statute invites states to submit creative proposals for integrated care plans serving dually eligible populations, or elderly citizens qualifying for both Medicare and Medicaid. The new Center for Medicare and Medicaid Innovation, a branch of the federal Centers for Medicare and Medicaid Services, is testing these innovative payment and service delivery models, looking for those that save money, keep patients at home, and provide the best quality of care possible.

The current Programs of All-Inclusive Care for the Elderly (PACE) may provide the most useful insight into the coordinated long-term care programs of tomorrow. Each PACE

consists of a network of health care and social service providers who assume full financial risk for an elderly population within their geographic area. They receive monthly payments per elderly participant from Medicare and Medicaid, and they have a financial incentive to keep their enrollees at home and as healthy as possible because that's how they earn a profit. Right now, such programs care for fewer than 25,000 elderly and disabled people in the U.S. because they often struggle to break even. If they can organize themselves more efficiently in the future, they may soon be caring for millions.

*

Once Jackie has persuaded Ruth to change into her pajamas in the basement, she goes upstairs to rinse a pot in the kitchen sink, fetch her black jacket, and exit through the backdoor with the dogs. Lighting a cigarette, she takes a pull, leans against the outdoor table, and exhales. Zorro and Kiwi roam the backyard, their snouts to the ground in search of squirrels. The sky is cloudless, starry, open.

Jackie extinguishes her smoke and tosses it in an ashtray on the patio that contains seven other butts. She allows herself to smoke up to eight cigarettes a day. She's already hit today's stress and nicotine limits.

When she goes to open the back door, which she usually keeps slightly ajar, she realizes that I've closed it by mistake. We are locked out, and she can't recall the code to the garage. She bangs on the door and nearby window, shouting Aaron's name, knowing all the while that he won't hear her voice over the sound effects of his video games. She walks around to the house's stately front facade and rings the doorbell. No answer. Spotting a neighbor whose brother knows the code to her garage door, she calls out to him. He tells her the man she's looking for isn't home. Just as I begin to phone Ben on my cell, she remembers

the code herself. She sighs, relieved by the evidence that her memory isn't waning.

Inside, Ruth has climbed to the top of the basement stairs in search of her daughter. Her green eyes latch onto Jackie. Ruth, like other Alzheimer's sufferers, is terrified of being alone, of being cut off for even a few seconds from the familiar. Jackie has complained about the way Ruth stares at her with the same look that Jackie's old boxer-pitbull, Buster, used to have. The "constant surveillance," Jackie says, drives her crazy.

Flustered by her unplanned detour and Ruth's fixed gaze, Jackie now dives into the evening routine: she strips the fitted sheet from Ruth's bed, revealing the 20-year-old hospital pad beneath; replaces the linens; and escorts Ruth into the cramped bathroom to supervise her washing. Their muffled voices emerge from behind the door, Jackie's strident, Ruth's a low grumble. Jackie retrieves Ruth's pajamas from her bedroom, and then — realizing the dogs are still outside — she goes upstairs to let them into the house.

By the time Jackie comes back down, her impatience is beginning to rattle her the way an oversized load unsteadies a washing machine. Ruth, prepared to ditch her bedtime routine before it's finished, steps tentatively out of the bathroom in a white t-shirt and blue- and green-striped pants, but Jackie shoves her back in, a little too firmly.

"Everything is at a glacial speed, and I'm, like, extremely fast, so I have no patience for this," Jackie says.

As exasperated as Jackie has become, she takes the time to collect a pair of scissors from upstairs. She has noticed that the legs of Ruth's pajama pants are dragging on the floor. With Ruth standing in the in-between room, Jackie kneels at her feet, scissors in hand, but decides, at the last minute, to fold the hems instead of cutting them. She rises and kisses Ruth on her wrinkled brow.

“I love you,” Jackie says.

Satisfied, Ruth plods into her bedroom. It is 7:49 p.m. As she starts to close the door, she casts her voice through the sliver of open space that remains: “Good night. I love you, too.”

*

Sociologists often say that caregiving has the potential to be transformative — to grant the caregiver a sense of usefulness, meaning, and closure. Jackie isn’t a very religious person, but she believes that caregiving is God’s way of releasing her from her emotional attachment to Ruth. She has struggled to let go of that especially tight bond in adulthood. She and her mother were all each other had for so long. “I think God has given me, literally, this torture,” Jackie says, “so that when I let go, I can just say goodbye and not have any remorse.”

While dementia patients might not physically die until years after their initial diagnosis, they experience what experts call a slow psychological death. Novelist Jonathan Franzen, reflecting on his father’s last years, notes that Alzheimer’s is a prism refracting death into a spectrum of its parts: death of autonomy, memory, self-consciousness, personality, and body.

Jackie, for her part, has already begun to mourn for Ruth. She has been disengaging herself from Ruth ever since her mother started to lose her emotional and social skills; she has experienced depression, grief, and loss long before Ruth’s inevitable death. She is emotionally prepared.

But anticipatory grief makes it hard to prepare for the care recipient’s death in more pragmatic ways. Sociologists, medical professionals, and attorneys recommend that dementia patients and their families make future health care plans soon after diagnosis, to spare caregivers the burden of making the difficult decisions later on. In New York State, hospitals give every patient a form, a kind of abbreviated living will, to appoint a family member as her

health care proxy and indicate any instructions she may have for that agent, such as a do-not-resuscitate order. When she can no longer articulate her medical preferences, her proxy has the legal power to act as a surrogate decision-maker on her behalf.

The challenge for the dementia patient's proxy is how to make decisions with respect for her dignity, wishes, and values, all of which change with her life experiences and decreasing cognitive capacities. Although "substituted judgment" — making the same decision we believe the person would make if she were still able — has long served as the ethical solution to the challenge, it often proves impossible to apply broad preferences (such as, "I don't want aggressive medical technologies used to prolong my life if I am dying") to particular clinical situations. Studies have shown that when cognitizant patients are asked if they want their advance directives followed closely or if they would prefer their family to do what they feel is best at the time, most choose the latter.

*

The Ms have been shopping for long-term care insurance because Ben is almost 62 and Jackie is 52. The specter of dementia haunts Jackie as she plans ahead, and she insists that her kids will not be caring for her and her husband in their old age.

"No way," she says. Having watched Jackie struggle to care for Ruth in her own home, Gabby and Aaron will not be doing the same for their parents. Gabby, who minds Ruth for Jackie from time to time, has found her grandmother's presence at home annoying and stressful. She offers her frazzled mom emotional support when necessary, but she also tells Jackie she clings to the past and takes on more responsibility than she can manage. Gabby insists that Ruth belongs in a nursing home facility. Aaron, on the other hand, mostly ignores Ruth; if she nags him while he's in the basement, he casually promises to do whatever she asks

of him, but fails to follow through.

Jackie doesn't want to haunt her children like her mother has. She insists she will be satisfied with a clean room wherever they decide to lodge her and Ben, even if its only view is a parking lot.

When Jackie returns to her kitchen after putting Ruth to bed, she finds Ben nibbling at the dinner that has been left in bowls on the counter for him and Gabby. They chat as Jackie rinses the dishes in the sink and loads the dishwasher.

Ben has accepted Ruth's presence in his home for the last three years because he empathizes with Jackie's connection to her mother. His own parents, whom he hasn't had the chance to visit since Ruth moved in, live in Iran, and he calls them frequently. Lately though, Ben's tolerance for his mother-in-law's needs is fading. "He's had enough — I can see it," Jackie says. When husband and wife do wrangle the rare night-out, Ben senses that Jackie can't stop thinking about Ruth and the ways in which she's likely aggravating her babysitter. When they squabble, Ben reminds Jackie of all the experiences they might be having now that their children are grown and their finances are plentiful — if it weren't for Ruth.

Ben retreats to his home office and Jackie plunks down in her favorite living-room chair, where Gabby will find her when she returns home. Jackie sits with her bent legs arched over the upholstered arm, and her iPad, a Mother's Day gift, in her lap. The room is faintly illuminated by light from the kitchen and the tablet, which is playing, with subtitles, an episode of the miniseries *The Forsyte Saga*. Now and then, Jackie's iPhone glows with a text from a friend who is working a late shift at the Harbor House nursing home in Oyster Bay.

The subject of their conversation is a morbid one: earlier in the day, a woman walking her dog along a beach 10 minutes from Jackie's home discovered the skeletal remains of a

female homicide victim. Jackie is both alarmed and fascinated. In her day-to-day routine, she has come to know death not as a sudden extraction from life but as a force that creeps slowly toward the living.

“This sounds terrible, but I’m ready for her to go,” Jackie has admitted. “I’ve actually reached the point where I go to bed at night and say, ‘I hope this is it.’ How fucked up is that? It’s so messed up, and it’s the God’s honest truth.”

At 9:27 p.m., she sets the timer on her Cuisinart coffee maker for 6 a.m. tomorrow morning and climbs up the staircase to her bedroom, yawning.

*

A week before I leave Milwaukee for the summer, my grandfather tells me he has an errand to run. At my insistence, he elaborates: something’s wrong with his cell phone, so he needs to visit his old mobile store — in Martinsville, New Jersey.

For Grandpa, time has doubled back on itself, erasing the months since his move to a retirement community 700 miles away from his old home. For me, it’s still advancing: I have a recital of classical arias to sing before his new neighbors in a few hours.

Sidestepping me, Grandpa walks to the front door of his apartment, where he claims a set of car keys dangling from a hook. If he had his way, he might drive halfway across the country. In fact, in his universe, a wormhole outside the apartment just might whisk him away to his old doorstep in New Jersey.

In my universe, there are no such miracles. There is only panic. Survival-mode, can-barely-see-straight panic. Grandpa might get lost. He might die in an accident. I definitely don’t have the time for this now.

I grab the keys from his right hand, dash into the spare bedroom where I’ve been

sleeping, and hide them in a drawer. Grandpa follows. We tussle at the doorway and wrench each other's wrists and Grandpa demands to know where I've put the keys and I deny they're somewhere behind me. As I release him, he says, "Bitch." He staggers into the room, ransacking my belongings in fury while I phone my dad, asking him to pacify Grandpa over the landline.

After Dad diffuses the skirmish from our home in New York, he tells me to focus on my singing, but no notes come from my mouth, only sobs. Sobs of relief and of loss.

I have lost Grandpa to a reality of his declining brain's invention, where time is recursive and he remains a rational man. I have since learned, from Jackie and Ruth, that it's a mistake to tug him back into mine.

I can, however, join him in compromise. I should have told him, Grandpa, let's run that errand together. This afternoon, we'll pretend that you're the one in charge. I'll sit behind the wheel, and you'll tell me where you want to go.

Endnotes

1. Pg. 3: "*A few months...likely Alzheimer's Disease.*" Britton 2012.
2. Pg. 3: "*The traffic is...the same route.*" Alzheimer's Association 2013.
3. Pg. 4: "*You're going to...figure it serves.*" M. 2013.
4. Pg. 4: "*Ok, you'll figure...out,' Jackie says.*" Ibid.
5. Pg. 5: "*She was totally...it,' Jackie admits.*" Ibid.
6. Pg. 5: "*in Jackie's opinion was...of this world.*" T. 2013.
7. Pg. 5: "*(Weighing in the...cover the cost.*" M. 2013.
8. Pg. 6: "*The demented elderly...hide it anymore.*" Ibid.
9. Pg. 7: "*Of Jackie's decision...to step into.*" T. 2013.
10. Pg. 7: "*Of course,' Eleanor...actually living it.*" Ibid.
11. Pg. 7: "*Nearly 3.8 million...to 9.1 million.*" Belluck 2013
12. Pg. 7: "*The U.S. population...older have it.*" Ostwald 2006.
13. Pg. 7: "*As the number...trillion in 2050.*" Wolff 2012.
14. Pg. 7: "*Medicaid, a program...of long-term care.*" Houser, Fox-Grage, Ujvari 2012.
15. Pg. 8: "*Medicaid dollars, on...a nursing home.*" Ibid.
16. Pg. 8: "*(Each case of...impartial study says.)*" Belluck 2013.
17. Pg. 8: "*In 2011, the...billion in 1996.*" Feinberg et al. 2011.
18. Pg. 8: "*In 1990, there...buckling under pressure.*" Ostwald 2006.
19. Pg. 9: "*In 2010, they...disability services programs.*" Feinberg et al. 2011.
20. Pg. 9: "*The irreducible truth...with dementia alone.*" Kudish 2012.
21. Pg. 9: "*Maybe I should...the comb advances.*" Gomes 2013.
22. Pg. 9: "*She has apraxia...her speaking ability.*" Mace and Rabins 2011.
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24. Pg. 9: "*I speak her...one else did.*" M. 2012.
25. Pg. 10: "*It's beautiful,' says...Ruth's shellacked 'do.*" Ibid 2013.
26. Pg. 10: "*Times were hard...second oldest sibling.*" Deeks 2012.
27. Pg. 10: "*If she wanted...fresh,' Barbara says.*" Ibid.
28. Pg. 11: "*Barbara insists that...finally in construction.*" Ibid.
29. Pg. 11: "*His sister describes...her only son.*" M. 2012.
30. Pg. 11: "*She was so...uptight,' Jackie says.*" Ibid.
31. Pg. 12: "*Barbara, who calls...to help you.*" Deeks 2012.
32. Pg. 12: "*Outside Dr. Wong's...bunch of bullshit.*" M. 2013.
33. Pg. 13: "*Ma, do you... 'Yeah,' she said.*" M. and Gomes 2013.
34. Pg. 14: "*You're cold,' she...bending further forward.*" Gomes 2013.
35. Pg. 14: "*Jacke has names...has given her.*" M. 2012.
36. Pg. 15: "*You have the...keeps her busy.*" Ibid 2013.
37. Pg. 15: "*When German psychiatrist...one's later years.*" Kaufman 2006.
38. Pg. 15: "*Thirty-three years earlier...the top first.*" Ballenger 2006.
39. Pg. 15: "*In 1909, Ignatz...of the brain.*" Kaufman 2006.
40. Pg. 15-6: "*In the aftermath...they used to.*" Ballenger 2006.
41. Pg. 16: "*The experience of aging...through basic research.*" Ibid.
42. Pg. 17: "*The promotional copy... 'The Living Death.'*" Ibid.
43. Pg. 17: "*I should have...she probably hasn't.*" Gomes 2013.
44. Pg. 18-9: "*When the U.S....to the contrary.*" Fortinsky 2013.

45. Pg. 19: *"Nearly three out...community-based services."* Houser, Fox-Grage, Ujvari 2012.
46. Pg. 19: *"Families who choose...and disabled Americans."* Bodenheimer and Grumbach 2012.
47. Pg.19-20: *"The U.S. government...case management services."* Ibid.
48. Pg. 20: *"Medicaid pays for...\$20,000 or less."* Friedman 2013.
49. Pg. 20: *"And those aging...and coverage limits."* Bodenheimer and Grumbach 2012.
50. Pg. 20: *"Established in 1979..."* Zarit 2006.
51. Pg. 20: *"...the voluntary health...no longer can."* Kudish 2013.
52. Pg. 20-1: *"But sometimes, Kudish...by their responsibilities."* Ibid.
53. Pg. 21: *"In Fortinsky's opinion...in group therapy."* Fortinsky 2013.
54. Pg. 21: *"She hasn't gone...as 'miracle workers.'"* M. 2012.
55. Pg. 21: *"Adult day service...in their communities."* Administration on Aging 2012.
56. Pg. 21: *"By now, Area...for their caregivers."* Met Life Mature Market Institute 2010.
57. Pg. 21: *"The private-pay...\$65 in 2012."* Genworth 2013.
58. Pg. 21-2: *"The suggested daily...much less costly."* Craig 2012.
59. Pg. 23: *"As recently as...my head straight."* M. 2012.
60. Pg. 23: *"It may be...of constant nightmare."* Wolff 2012.
61. Pg. 24: *"Cognitive reserve is...times of stress."* Hu 2013.
62. Pg. 24: *"It allows humans...deficits are revealed."* Lipton 2013.
63. Pg. 24-5: *"In the brain...need to survive."* Alzheimer's Association 2013.
64. Pg. 25: *"As plaques and...verify their hypotheses."* Mace and Rabins 2011.
65. Pg. 25: *"Research has proven...and tau proteins."* Lipton 2013.
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70. Pg. 26: *"In the meantime...Einstein Aging Study."* Lipton 2013.
71. Pg. 29: *"In the opinion...provocatively calls caregiving."* Wolff 2012.
72. Pg. 29: *"Caregivers may endure...has on them."* Feinberg et al. 2011.
73. Pg. 29: *"Research has show...guilty at others."* Zarit 2006.
74. Pg. 29: *"If Mom wets...out the door."* M. 2012.
75. Pg. 29: *"Some caregivers have...their charges' accounts."* Consumer Reports 2012.
76. Pg. 29-30: *"The impact of...of their lifespans."* Butler 2010.
77. Pg. 30: *"But Yale assistant...experience most acutely."* Monin 2013.
78. Pg. 30: *"UConn's Richard Fortinsky...aims to fix."* Fortinsky 2013.
79. Pg. 30: *"The statue invites...of care possible."* U.S. Congress 2010.
80. Pg. 31: *"Each PACE consists...earn a profit."* Fortinsky 2013.
81. Pg. 31: *"Right now, such...to break even."* Bodenheimer and Grumbach 2012.
82. Pg. 33: *"Novelist Jonathan Franzen...personality, and body."* Franzen 2001.
83. Pg. 34: *"In New York...on her behalf."* Friedman 2013.
84. Pg. 34: *"Although 'substituted judgment'...choose the latter."* Osman 2006.
85. Pg. 35: *"'No way,' she...the parking lot."* M. 2012.
86. Pg. 35-6: *"'This sounds terrible...God's honest truth.'"* Ibid.

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