MY FATHER'S BRAIN;  
What Alzheimer's takes away.

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Here's a memory. On an overcast morning in February, 1996, I received in the mail from my mother, in St. Louis, a Valentine's package containing one pinkly romantic greeting card, two four-ounce Mr. Goodbars, one hollow red filigree heart on a loop of thread, and one copy of a neuropathologist's report on my father's brain autopsy.

I remember the bright-gray winter light that morning. I remember leaving the candy, the card, and the ornament in my living room, taking the autopsy report into my bedroom, and sitting down to read it. The brain (it began) weighed 1,255 gm and showed parasagittal atrophy with sulcal widening. I remember translating grams into pounds and pounds into the familiar shrink-wrapped equivalents in a supermarket meat case. I remember putting the report back into its envelope without reading any further.

Some years before he died, my father had participated in a study of memory and aging at Washington University, and one of the perks for participants was a post-mortem brain autopsy, free of charge. I suspect that the study offered other perks of monitoring and treatment which had led my mother, who loved freebies of all kinds, to insist that my father volunteer for it. Thrift was also probably her only conscious motive for including the autopsy report in my Valentine's package. She was saving thirty-two cents' postage.

My clearest memories of that February morning are visual and spatial: the yellow Mr. Goodbar, my shift from living room to bedroom, the late-morning light of a season as far from the winter solstice as from spring. I'm aware, however, that even these memories aren't to be trusted. According to the latest theories, which are based on a wealth of neurological and psychological research in the last few decades, the brain is not an album in which memories are stored discretely like unchanging photographs. Instead, a memory is, in the phrase of the psychologist Daniel L. Schacter, a "temporary constellation" of activity-a necessarily approximate excitation of neural circuits that bind a set of sensory images and semantic data into the momentary sensation of a remembered whole. These images and data are seldom the exclusive property of one particular memory. Indeed, even as my experience on that Valentine's morning was unfolding, my brain was relying on preexisting categories of "red" and "heart" and "Mr. Goodbar"; the gray sky in my windows was familiar from a thousand other winter mornings; and I already had millions of neurons devoted to a picture of my mother-her stinginess with postage, her romantic attachments to her children, her lingering anger toward my father, her
weird lack of tact, and so on. What my memory of that morning therefore consists of, according to the latest models, is a set of hardwired neuronal connections among the pertinent regions of the brain, and a predisposition for the entire constellation to light up—chemically, electrically—when any one part of the circuit is stimulated. Speak the words "Mr. Goodbar" and ask me to free-associate, and if I don't say "Diane Keaton" I will surely say "brain autopsy."

My Valentine's memory would work this way even if I were dredging it up now for the first time ever. But the fact is that I've re-remembered that February morning countless times since then. I've told the story to my brothers. I've offered it as an Outrageous Mother Incident to friends of mine who enjoy that kind of thing. I've even, shameful to report, told people I hardly know at all. Each succeeding recollection and retelling reinforces the constellation of images and knowledge that constitute the memory. At the cellular level, according to neuroscientists, I'm burning the memory in a little deeper each time, strengthening the dendritic connections among its components, further encouraging the firing of that specific set of synapses. One of the great adaptive virtues of our brains, the feature that makes our gray matter so much smarter than any machine yet devised (my laptop's cluttered hard drive or a World Wide Web that insists on recalling, in pellucid detail, a "Beverly Hills 90210" fan site last updated on 11/20/98), is our ability to forget almost everything that has ever happened to us. I retain general, largely categorical memories of the past (a year spent in Spain; various visits to Indian restaurants on East Sixth Street) but relatively few specific, episodic memories. Those memories that I do retain I tend to revisit and, thereby, strengthen. They become—morphologically, electrochemically—part of the architecture of my brain.

This model of memory, which I've presented here in a rather loose layperson's summary, excites the amateur scientist in me. It feels true to the twinned fuzziness and richness of my own memories, and it inspires awe with its image of neural networks effortlessly self-coordinating, in a massively parallel way, to create my ghostly consciousness and my remarkably sturdy sense of self. It seems to me lovely and postmodern. The human brain is a web of a hundred billion neurons, maybe as many as two hundred billion, with trillions of axons and dendrites exchanging quadrillions of messages by way of at least fifty different chemical transmitters. The organ with which we observe and make sense of the universe is, by a comfortable margin, the most complex object we know of in that universe.

And yet it's also a lump of meat. At some point, maybe later on that same Valentine's Day, I forced myself to read the entire pathology report. It included a "Microscopic Description" of my father's brain:

Sections of the frontal, parietal, occipital, and temporal cerebral cortices showed numerous senile plaques, prominently diffuse type, with minimal numbers of neurofibrillary tangles. Cortical Lewy bodies were easily detected in H&E stained material. The amygdala demonstrated plaques, occasional tangles and mild neuron loss.

In the notice that we had run in local newspapers nine months earlier, my mother insisted that we say my father had died "after long illness." She liked the phrase's formality and reticence, but it was hard not to hear her grievance in it as well, her emphasis on "long." The pathologist's identification of senile plaques in my father's brain served to confirm, as only an autopsy could, the fact with which she'd struggled daily for many years: like millions of other Americans, my father had had Alzheimer's disease.

This was his disease. It was also, you could argue, his story. But you have to let me tell it.

Alzheimer's is a disease of classically "insidious onset." Since even healthy people become more forgetful as they age, there's no way to pinpoint the first memory to fall victim to it. The problem was especially vexed in the case of my father, who not only was depressive and reserved and slightly deaf but also was taking strong medicines for other ailments. For a long time, it was possible to chalk up his non sequiturs to his hearing impairment, his forgetfulness to his depression, his hallucinations to his medicines; and chalk them up we did.

My memories of the years of my father's initial decline are vividly about things other than him. Indeed, I'm somewhat appalled by how large I loom in my own memories, how peripheral my parents are. But I was living far from home in those years. My information came mainly from my mother's complaints about my father, and these complaints...
I took with a grain of salt; she'd been complaining to me pretty much all my life.

My parents' marriage was, it's safe to say, less than happy. They stayed together for the sake of their children and for want of hope that divorce would make them any happier. As long as my father was working, they enjoyed autonomy in their respective fiefdoms of home and workplace, but after he retired, in 1981, they commenced a round-the-clock performance of "No Exit" in their comfortably furnished suburban house. I arrived for brief visits like a U.N. peacekeeping force to which each side passionately presented its case against the other.

In contrast to my mother, who was hospitalized nearly thirty times in her life, my father had perfect health until he retired. His parents and uncles had lived into their eighties and nineties, and he, Earl Franzen, fully expected himself to be around at ninety "to see," as he liked to say, "how things turn out." (His anagrammatic namesake Lear imagined his last years in similar terms: listening to "court news," with Cordelia, to see "who loses and who wins; who's in, who's out.") My father had no hobbies and few pleasures besides eating meals, seeing his children, and playing bridge, but he did take a narrative interest in life. He watched a staggering amount of TV news. His ambition for old age was to follow the unfolding histories of the nation and his children for as long as he could.

The passivity of this ambition, the sameness of his days, tended to make him invisible to me. From the early years of his mental decline I can dredge up exactly one direct memory: watching him, toward the end of the eighties, struggle and fail to calculate the tip on a restaurant bill.

Fortunately, my mother was a great writer of letters. My father's passivity, which I regarded as regrettable but not really any of my business, was a source of bitter disappointment to her. As late as the fall of 1989—a season in which, according to her letters, my father was still playing golf and undertaking major home repairs—the terms of her complaints remained strictly personal:

It is extremely difficult living with a very unhappy person when you know you must be the major cause of the unhappiness. Decades ago when Dad told me he didn't believe there is such a thing as love (that sex is a "trap") and that he was not cut out to be a "happy" person I should have been smart enough to realize there was no hope for a relationship satisfactory to me.

This letter dates from a period during which the theatre of my parents' war had shifted to the issue of my father's hearing impairment. My mother maintained that it was inconsiderate not to wear a hearing aid; my father complained that other people lacked the consideration to "speak up." The battle culminated Pyrrhically, in his purchase of a hearing aid that he then declined to wear. Here again, my mother constructed a moral story of his "stubbornness" and "vanity" and "defeatism"; but it's hard not to suspect, in hindsight, that his faulty ears were already serving to camouflage more serious trouble.

A letter from January, 1990, contains my mother's first written reference to this trouble:

Last week one day he had to skip his breakfasttime medication in order to take some motor skills tests at Wash U. where he is in the Memory & Ageing study. That night I awakened to the sound of his electric razor, looked at the clock & he was in the bathroom shaving at 2:30 AM.

Within a few months, my father was making so many mistakes that my mother was forced to entertain other explanations:

Either he's stressed or not concentrating or having some mental deterioration but there have been quite a few incidents recently that really worry me. He keeps leaving the car door open or the lights on & twice in one week we had to call triple A & have them come out & charge the battery (now I've posted signs in the garage & that seems to have helped). . . . I really don't like the idea of leaving him in the house alone for more than a short while.

My mother's fear of leaving him alone assumed greater urgency as the year dragged on. Her right knee was worn
out, and, because she already had a steel plate in her leg from an earlier fracture, she was facing complicated surgery followed by prolonged recovery and rehab. Her letters from late 1990 and early 1991 are marked by paragraphs of agonizing over whether to have surgery and how to manage my father if she did:

Were he in the house alone more than overnight with me in the hospital I would be an absolute basket case as he leaves the water running, the stove on at times, lights on everywhere, etc. . . . I check & recheck as much as I can on most things lately but even so many of our affairs are in a state of confusion & what really is hardest is his resentment of my intrusion-"stay out of my affairs!!" He does not accept or realize my wanting to be helpful & that is the hardest thing of all for me.

At the time, I'd recently finished my second novel, and so I offered to stay with my father while my mother had her operation. To steer clear of his pride, she and I agreed to pretend that I was coming for her sake, not his. What's odd, though, is that I was only half-pretending. My mother's characterization of my father's incapacity was compelling, but so was my father's portrayal of my mother as an alarmist nag. I went to St. Louis because, for her, his incapacity was absolutely real; once there, I behaved as if, for me, it absolutely wasn't.

My mother was in the hospital for nearly five weeks. Strangely, although I'd never lived alone with my father for so long and never would again, I can now remember almost nothing specific about my stay with him; I have a general impression that he was somewhat quiet, maybe, but otherwise completely normal. Here, you might think, was a direct contradiction of my mother's earlier reports. And yet I have no memory of being bothered by the contradiction. What I do have is a copy of a letter that I wrote to a friend while in St. Louis. In the letter, I mention that my father has had his medication adjusted and now everything is fine.

Wishful thinking? Yes, to some extent. But one of the basic features of the mind is its keenness to construct wholes out of fragmentary parts. We all have a blind spot in our vision where the optic nerve attaches to the retina, but our brain unfailingly registers a seamless world around us. We catch part of a word and hear the whole. We see expressive faces in floral-pattern upholstery; we constantly fill in blanks. In a similar way, I think I was inclined to interpolate across my father's silences and mental absences and to persist in seeing him as the same old wholly whole Earl Franzen. I still needed him to be an actor in my story of myself. In my letter to my friend, I describe a morning practice session of the St. Louis Symphony that my mother insisted my father and I attend so as not to waste her free tickets to it. After the first half of the session, in which the very young Midori nailed the Sibelius violin concerto, my father sprang from his seat with miserable geriatric agitation. "So," he said, "we'll go now." I knew better than to ask him to sit through the Charles Ives symphony that was coming, but I hated him for what I took to be his philistinism. On the drive home, he had one comment about Midori and Sibelius. "I don't understand that music," he said. "What do they do-memorize it?"

Later that spring, my father was diagnosed with a small, slow-growing cancer in his prostate. His doctors recommended that he not bother treating it, but he insisted on a course of radiation. With a kind of referred wisdom about his own mental state, he became terrified that something was dreadfully wrong with him: that he would not, after all, survive into his nineties. My mother, whose knee continued to bleed internally six months after her operation, had little patience with what she considered his hypochondria. In September, 1991, she wrote:

I'm relieved to have Dad started on his radiation therapy & it forces him to get out of the house every day inserted here a smiley face -a big plus. . . . Actually, being so sedentary now (content to do nothing), he has had too much time to worry & think about himself-he NEEDS distractions! . . . More & more I feel the greatest attributes anyone can have are (1), a positive attitude & (2), a sense of humor-wish Dad had them.

There ensued some months of relative optimism. The cancer was eradicated, my mother's knee improved, and her native hopefulness returned to her letters. She reported that my father had taken first place in a game of bridge: "With his confusion cleared up & his less conservative approach to the game he is doing remarkably well & it's about the only thing he enjoys (& can stay awake for!)." But my father's anxiety about his health did not abate; he had stomach pains that he was convinced were caused by cancer. Gradually, the import of the story my mother was telling me migrated
from the personal and the moral toward the psychiatric. "The past six months we have lost so many friends it is very unsettling-part of Dad's nervousness & depression I'm sure," she wrote in February, 1992. The letter continued:

Dad's internist, Dr. Rouse, has about concluded what I have felt all along regarding Dad's stomach discomfort (he's ruled out all clinical possibilities). Dad is (1) terribly nervous, (2) terribly depressed & I hope Dr. Rouse will put him on an anti-depressant. I know there has to be help for this. . . . If he won't go for counseling (suggested by Dr. Weiss) perhaps he now will accept pills or whatever it takes for nervousness & depression.

For a while, the phrase "nervousness & depression" was a fixture of her letters. Prozac briefly seemed to lift my father's spirits, but the effects were short-lived. Finally, in July, 1992, to my surprise, he agreed to see a psychiatrist.

My father had always been supremely suspicious of psychiatry. He viewed therapy as an invasion of privacy, mental health as a matter of self-discipline, and my mother's increasingly pointed suggestions that he "talk to someone" as acts of aggression- little lobbed grenades of blame for their unhappiness as a couple. It was a measure of his desperation that he had voluntarily set foot in a psychiatrist's office.

In October, when I stopped in St. Louis on my way to Italy, I asked him about his sessions with the doctor. He made a hopeless gesture with his hands. "He's extremely able," he said. "But I'm afraid he's written me off."

The idea of anybody writing my father off was more than I could stand. From Italy, I sent the psychiatrist a three-page appeal for reconsideration, but even as I was writing it the roof was caving in at home. "Much as I dislike telling you," my mother wrote in a letter faxed to Italy, "Dad has regressed terribly. Medicine for the urinary problem a urologist is treating in combination with medication for depression and nervousness blew his mind again and the hallucinating, etc., was terrible." There had been a weekend with my Uncle Erv in Indiana, where my father, removed from his familiar surroundings, unleashed a night of madness that culminated in my uncle's shouting into his face, "Earl, my God, it's your brother, Erv, we slept in the same bed!" Back in St. Louis, my father had begun to rage against the retired lady, Mrs. Pryble, whom my mother had engaged to sit with him two mornings a week while she ran errands. He didn't see why he needed sitting, and, even assuming that he did need sitting, he didn't see why a stranger, rather than his wife, should be doing it. He'd become a classic "sundowner," dozing through the day and rampaging in the wee hours.

There followed a dismal holiday when my wife and I finally intervened on my mother's behalf and put her in touch with a geriatric social worker, and my mother urged my wife and me to tire my father out so that he would sleep through the night without psychotic incident, and my father sat stone-faced by the fireplace or told grim stories of his childhood while my mother fretted about the expense, the prohibitive expense, of sessions with a social worker. But even then, as far as I can remember, nobody ever said "dementia." In all my mother's letters to me, the word "Alzheimer's" appears exactly once, in reference to an old woman I worked for as a teen-ager.

I remember my suspicion and annoyance, fifteen years ago, when the term "Alzheimer's disease" was first achieving currency. It seemed to me another instance of the medicalization of human experience, the latest entry in the ever-expanding nomenclature of victimhood. To my mother's news about my old employer I replied, "What you describe sounds like the same old Erika, only quite a bit worse; and that's not how Alzheimer's is supposed to work, is it? I spend a few minutes every month fretting about ordinary mental illness being trendily misdiagnosed as Alzheimer's."

From my current vantage, where I spend a few minutes every month fretting about what a self-righteous thirty-year-old I was, I can see my reluctance to apply the term Alzheimer's to my father as a way of protecting the specificity of Earl Franzen from the generality of a nameable condition. Conditions have symptoms; symptoms point to the organic basis of everything we are. They point to the brain as meat. And, where I ought to recognize that, yes, the brain is meat, I seem instead to maintain a blind spot across which I then interpolate stories that emphasize the more soul-like aspects of the self. Seeing my afflicted father as a set of organic symptoms would invite me to understand the
healthy Earl Franzen (and the healthy me) in symptomatic terms as well-to reduce our beloved personalities to finite sets of neurochemical coordinates. Who wants a story of life like that?

Even now, I feel uneasy when I gather facts about Alzheimer's. Reading, for example, David Shenk's excellent new book, "The Forgetting: Alzheimer's: Portrait of an Epidemic," I'm reminded that when my father got lost in his own neighborhood, or forgot to flush the toilet, he was exhibiting symptoms identical to those of millions of other afflicted people. There can be comfort in having company like this, but I'm sorry to see the personal significance drained from certain mistakes of my father's, like his confusion of my mother with her mother, which struck me at the time as singular and orphic, and from which I gleaned all manner of important new insights into my parents' marriage. My sense of private selfhood turns out to have been illusory.

Senile dementia has been around for as long as people have had the means of recording it. While the average human life span remained low and old age was a comparative rarity, senility was considered a natural by-product of aging-perhaps the result of sclerotic cerebral arteries. The German neuropathologist Alois Alzheimer believed he was witnessing an entirely new variety of mental illness when, in 1901, he admitted to his clinic a fifty-one-year-old woman, Auguste D., who was suffering from bizarre mood swings and severe memory loss and who, in Alzheimer's initial examination of her, gave problematic answers to his questions:

"What is your name?" "Auguste." "Last name?" "Auguste." "What is your husband's name?" "Auguste, I think."

When Auguste D. died in an institution, four years later, Alzheimer availed himself of recent advances in microscopy and tissue staining and was able to discern, in slides of her brain tissue, the striking dual pathology of her disease: countless sticky-looking globs of "plaque," and countless neurons engulfed by "tangles" of neuronal fibrils. Alzheimer's findings greatly interested his patron Emil Kraepelin, then the dean of German psychiatry, who was engaged in a fierce scientific battle with Sigmund Freud and Freud's psycho-literary theories of mental illness. To Kraepelin, Alzheimer's plaques and tangles provided welcome clinical support for his contention that mental illness was fundamentally organic. In his "Handbook of Psychiatry" he dubbed Auguste D.'s condition Morbus Alzheimer.

For six decades after Alois Alzheimer's autopsy of Auguste D., even as breakthroughs in disease prevention and treatment were adding fifteen years to life expectancy in developed nations, Alzheimer's continued to be viewed as a medical rarity a la Huntington's disease. David Shenk tells the story of an American neuropathologist named Meta Neumann who, in the early fifties, autopsied the brains of two hundred and ten victims of senile dementia and found sclerotic arteries in few of them, plaques and tangles in the majority. Here was ironclad evidence that Alzheimer's was far more common than anyone had guessed; but Neumann's work appears to have persuaded no one. "They felt that Meta was talking nonsense," her husband recalled.

The scientific community simply wasn't ready to consider that senile dementia might be more than a natural consequence of aging. In the early fifties, there was no self-conscious category of "seniors," no explosion of Sun Belt retirement developments, no A.A.R.P., no Early Bird tradition at low-end restaurants; and scientific thinking reflected these social realities. Not until the seventies did conditions become ripe for a reinterpretation of senile dementia. By then, as Shenk says, "so many people were living so long that senility didn't feel so normal or acceptable anymore." Congress passed the Research on Aging Act in 1974, and established the National Institute on Aging, for which funding soon mushroomed. By the end of the eighties, at the crest of my annoyance with the clinical term and its sudden ubiquity, Alzheimer's had achieved the same social and medical standing as heart disease or cancer-and had the research-funding levels to show for it.

What happened with Alzheimer's in the seventies and the eighties wasn't simply a diagnostic paradigm shift. The number of new cases really is soaring. As fewer and fewer people drop dead of heart attacks or die of infections, more and more survive to become demented. Alzheimer's patients in nursing homes live much longer than other patients, at a cost of at least forty thousand dollars annually per patient; until they're institutionalized, they increasingly derange the lives of family members charged with caring for them. Already, five million Americans have the disease, and the
number could rise to fifteen million by 2050.

Because there's so much money in chronic illness, drug companies are investing feverishly in proprietary Alzheimer's research while publicly funded scientists file for patents on the side. But because the science of the disease remains cloudy (a functioning brain is not a lot more accessible than the center of the earth or the edge of the universe) nobody can be sure which avenues of research will lead to effective treatments. Early-onset Alzheimer's is usually linked to specific genes, but the vastly more common late-onset variety cannot be traced to a single factor. And the disease's etiology is like the proverbial elephant—it looks like an inflammation of the brain but also like a neurochemical imbalance but also like a disease of abnormal-protein deposition of the kind that occasionally strikes the heart and kidneys.

Treatments currently under study target each of these aspects. People taking cholesterol-reducing drugs or nonsteroidal anti-inflammatory drugs (like aspirin or Celebrex) may enjoy a lower risk of Alzheimer's. Those who already have the disease can sometimes be helped for a while with acetylcholine-boosting medications or antioxidants like Vitamin E. There is intense competition among drug companies to develop enzyme inhibitors that zero in on the abnormal proteins. On the immunological front, researchers at Elan Pharmaceuticals recently came up with the seemingly outlandish idea of a vaccine for Alzheimer's—of teaching the immune system to produce antibodies that attack and destroy amyloid plaques in the brain—and found that the vaccine not only prevented plaque formation in transgenic mice but actually reversed the mental deterioration of mice already addled by it. Over all, the feeling in the field seems to be that if you're under fifty you can reasonably expect to be offered effective drugs for Alzheimer's by the time you need them. Then again, twenty years ago, many cancer researchers were predicting a cure within twenty years.

David Shenk, who is comfortably under fifty, makes the case in "The Forgetting" that a cure for senile dementia might not be an unmitigated blessing. He notes, for example, that one striking peculiarity of the disease is that its sufferers often suffer less and less as it progresses. Caring for an Alzheimer's patient is gruellingly repetitious precisely because the patient himself has lost the cerebral equipment to experience anything as a repetition. Shenk quotes patients who speak of "something delicious in oblivion" and who report an enhancement of their sensory pleasures as they come to dwell in an eternal, pastless Now. If your short-term memory is shot, you don't remember, as you stoop to smell a rose, that you've been stooping to smell the same rose all morning.

As the psychiatrist Barry Reisberg first observed twenty years ago, the decline of an Alzheimer's patient mirrors in reverse the neurological development of a child. The earliest capacities a child develops—raising the head (at one to three months), smiling (two to four months), sitting up unassisted (six to ten months)—are the last capacities an Alzheimer's patient loses. Brain development in a growing child is consolidated through a process called myelinization, wherein the axonal connections between neurons are gradually strengthened by sheathings of the fatty substance myelin. Apparently, since the last regions of the child's brain to mature remain the least myelinated, they're the regions most vulnerable to the insult of Alzheimer's. The hippocampus, which processes short-term memories into long-term, is very slow to myelinize. This is why we're unable to form permanent episodic memories before the age of three or four, and why the hippocampus is where the plaques and tangles of Alzheimer's first appear. Hence the ghostly apparition of the middle-stage patient who continues to be able to walk and feed herself even as she remembers nothing from hour to hour. The inner child isn't inner anymore. Neurologically speaking, we're looking at a one-year-old.

Although Shenk tries valiantly to see a boon in the Alzheimer's patient's childish relief from responsibility and childlike focus on the Now, I'm mindful that becoming a baby again was the last thing my father wanted. The stories he told from his childhood, in northern Minnesota, were mainly (as befits a depressive's recollections) horrible: brutal father, unfair mother, endless chores, backwoods poverty, family betrayals, hideous accidents. He told me more than once, after his retirement, that his greatest pleasure in life had been going to work as an adult in the company of other men who valued his abilities. My father was an intensely private person, and privacy for him had the connotation of keeping the shameful content of one's interior life out of public sight. Could there have been a worse disease for him than Alzheimer's? In its early stages, it worked to dissolve the social connections that had saved him from the worst of his depressive isolation. In its later stages, it robbed him of the sheathing of adulthood, the means to hide the child
inside him. I wish he'd had a heart attack instead.

Still, shaky though Shenk's arguments for the brighter side of Alzheimer's may be, his core contention is harder to dismiss: senility is not merely an erasure of meaning but a source of meaning. For my mother, the losses of Alzheimer's both amplified and reversed long-standing patterns in her marriage. My father had always refused to open himself to her, and now, increasingly, he couldn't open himself. To my mother, he remained the same Earl Franzen napping in the den and failing to hear. She, paradoxically, was the one who slowly and surely lost her self, living with a man who mistook her for her mother, forgot every fact he'd ever known about her, and finally ceased to speak her name. He, who had always insisted on being the boss in the marriage, the maker of decisions, the adult protector of the childlike wife, couldn't help behaving like the child. Now the unseemly outbursts were his, not my mother's. Now she ferried him around town the way she'd once ferried me and my brothers. Task by task, she took charge of their life. And so, although my father's "long illness" was a crushing strain and disappointment to her, it was also an opportunity to grow slowly into an autonomy she'd never been allowed: to settle some very old scores.

As for me, once I accepted the scope of the disaster, the sheer duration of Alzheimer's forced me into unexpectedly welcome closer contact with my mother. I learned, as I might not have otherwise, that I could seriously rely on my brothers and that they could rely on me. And, strangely, although I'd always prized my intelligence and sanity and self-consciousness, I found that watching my father lose all three made me less afraid of losing them myself. I became a little less afraid in general. A bad door opened, and I found I was able to walk through it.

The door in question was on the fourth floor of Barnes Hospital, in St. Louis. About six weeks after my wife and I had put my mother in touch with the social worker and gone back East, my oldest brother and my father's doctors persuaded him to enter the hospital for testing. The idea was to get all the medications out of his bloodstream and see what we were dealing with underneath. My mother helped him check in and spent the afternoon settling him into his room. He was still his usual, semi-present self when she left for dinner, but that evening, at home, she began to get calls from the hospital, first from my father, who demanded that she come and remove him from "this hotel," and then from nurses who reported that he'd become belligerent. When she returned to the hospital in the morning, she found him altogether gone-raving mad, profoundly disoriented.

I flew back to St. Louis a week later. My mother took me straight from the airport to the hospital. While she spoke to the nurses, I went to my father's room and found him in bed, wide awake. I said hello. He made frantic shushing gestures and beckoned me to his pillow. I leaned over him and he asked me, in a husky whisper, to keep my voice down because "they" were "listening." I asked him who "they" were. He couldn't tell me, but his eyes rolled fearfully to scan the room, as if he'd lately seen "them" everywhere and were puzzled by "their" disappearance. When my mother appeared in the doorway, he confided to me, in an even lower whisper, "I think they've gotten to your mother."

My memories of the week that followed are mainly a blur, punctuated by a couple of life-changing scenes. I went to the hospital every day and sat with my father for as many hours as I could stand. At no point did he string together two coherent sentences. The memory that appears to me most significant in hindsight is a very peculiar one. It's lit by a dreamlike indoor twilight, it's set in a hospital room whose orientation and cramped layout are unfamiliar from any of my other memories, and it returns to me now without any of the chronological markers that usually characterize my memories. I'm not sure it even dates from that first week I saw my father in the hospital. And yet I am sure that I'm not remembering a dream. All memories, the neuroscientists say, are actually memories of memory, but usually they don't feel that way. Here's one that does. I remember remembering: my father in bed, my mother sitting beside it, me standing near the door. We've been having an anguished family conversation, possibly about where to move my father after his discharge from the hospital. It's a conversation that my father, to the slight extent that he can follow it, is hating. Finally, he cries out with passionate emphasis, as if he has had enough of all the nonsense, "I have always loved your mother. Always." And my mother buries her face in her hands and sobs.

This was the only time I ever heard my father say he loved her. I'm certain the memory is legitimate because the scene seemed to me immensely significant even at the time, and I then described it to my wife and brothers and
incorporated it into the story I was telling myself about my parents. In later years, when my mother insisted that my father had never said he loved her, not even once, I asked if she remembered that time in the hospital. I repeated what he'd said, and she shook her head uncertainly. "Maybe," she said. "Maybe he did. I don't remember that."

My brothers and I took turns going to St. Louis every few months. My father never failed to recognize me as someone he was happy to see. His life in a nursing home appeared to be an endless troubled dream populated by figments from his past and by his deformed and brain-damaged fellow-inmates; his nurses were less like actors in the dream than like unwelcome intruders on it. Unlike many of the female inmates, who at one moment were wailing like babies and at the next moment glowing with pleasure while someone fed them ice cream, my father never cried, and the pleasure he took in ice cream never ceased to look like an adult's. He gave me significant nods and wistful smiles as he confided to me fragments of nonsense to which I nodded as if I understood. His most consistently near-coherent theme was his wish to be removed from "this hotel" and his inability to understand why he couldn't live in a little apartment and let my mother take care of him.

For Thanksgiving that year, my mother and my wife and I checked him out of the nursing home and brought him home with a wheelchair in my Volvo station wagon. He hadn't been in the house since he'd last been living there, ten months earlier. If my mother had been hoping for a gratifying show of pleasure from him, she was disappointed; by then, a change of venue no more impressed my father than it does a one-year-old. We sat by the fireplace and, out of unthinking, wretched habit, took pictures of a man who, if he knew nothing else, seemed full of unhappy knowledge of how dismal a subject for photographs he was. The images are awful to me now: my father listing in his wheelchair like an unstrung marionette, eyes mad and staring, mouth sagging, glasses smeared with strobe light and nearly falling off his nose; my mother's face a mask of reasonably well-contained despair; and my wife and I flashing grotesquely strained smiles as we reach to touch my father. At the dinner table, my mother spread a bath towel over him and cut his turkey into little bites. She kept asking him if he was happy to be having Thanksgiving dinner at home. He responded with silence, shifting eyes, sometimes a faint shrug. My brothers called to wish him a happy holiday, and here, out of the blue, he mustered a smile and a hearty voice; he was able to answer simple questions and thanked them both for calling.

This much of the evening was typically Alzheimer's. Because children learn social skills very early, a capacity for gestures of courtesy and phrases of vague graciousness survives in many Alzheimer's patients long after their memories are shot. It wasn't so remarkable that my father was able to handle (sort of) my brothers' holiday calls. But consider what happened next, after dinner, outside the nursing home. While my wife ran inside for a geri chair, my father sat beside me and studied the institutional portal that he was about to reenter. "Better not to leave," he told me in a clear, strong voice, "than to have to come back." This was not a vague phrase; it pertained directly to the situation at hand, and it suggested an awareness of his larger plight and his connection to the past and to the future. He was requesting that he be spared the pain of being dragged back toward consciousness and memory. And, sure enough, on the morning after Thanksgiving, and for the remainder of our visit, he was as crazy as I ever saw him, his words a hash of random syllables, his body a big flail of agitation.

For David Shenk, one of the most illuminating aspects of Alzheimer's is its slowing down of death. Shenk likens the disease to a prism that refracts death into a spectrum of its otherwise tightly conjoined parts-death of autonomy, death of memory, death of self-consciousness, death of personality, death of body-and he subscribes to the most common trope of Alzheimer's: that its particular sadness and horror stem from the sufferer's loss of his or her "self" long before the body dies.

This seems mostly right to me. By the time my father's heart stopped, I'd been mourning him for years. And yet, when I consider his story, I wonder whether the various deaths can ever really be so separated, and whether memory and consciousness have such secure title, after all, to the seat of selfhood. I can't stop looking for meaning in the two years that followed his loss of his supposed "self," and I can't stop finding it.

I'm struck, above all, by the apparent persistence of his will. I'm powerless not to believe that he was exerting some
bodily remnant of his self-discipline, some reserve of strength in the sinews beneath both consciousness and memory, when he pulled himself together for the statement he made to me outside the nursing home. I'm powerless as well not to believe that his crash on the following morning, like his crash on his first night alone in a hospital, amounted to a relinquishment of that will, a letting go, an embrace of madness in the face of unbearable emotion. Although we can fix the starting point of his decline (full consciousness and sanity) and the end point (oblivion and death), his brain wasn't simply a computational device running gradually and inexorably amok. Where the subtractive progress of Alzheimer's might predict a steady downward trend like this-

-what I saw of my father's fall looked more like this:

He held himself together longer, I suspect, than it might have seemed he had the neuronal wherewithal to do. Then he collapsed and fell lower than his pathology may have strictly dictated, and he chose to stay low, ninety-nine per cent of the time. What he wanted (in the early years, to stay clear; in the later years, to let go) was integral to what he was. And what I want (stories of my father's brain that are not about meat) is integral to what I choose to remember and retell.

One of the stories I've come to tell, then, as I try to forgive myself for my long blindness to his condition, is that he was bent on concealing that condition and, for a remarkably long time, retained the strength of character to bring it off. My mother used to swear that this was so. He couldn't fool the woman he lived with, no matter how he bullied her, but he could pull himself together as long he had sons in town or guests in the house. The true solution of the conundrum of my stay with him during my mother's operation probably has less to do with my blindness than with the additional will he was exerting.

After the bad Thanksgiving, when we knew he was never coming home again, I helped my mother sort through his desk. (It's the kind of liberty you take with the desk of a child or a dead person.) In one of his drawers we found evidence of small, covert endeavors not to forget. There was a sheaf of papers on which he'd written the addresses of his children, one address per slip, the same address on several. On another slip he'd written the birth dates of his older sons-"Bob 1-13-48" and "TOM 10-15-50"-and then, in trying to recall mine (August 17, 1959), he had erased the month and day and made a guess on the basis of my brothers' dates: "JON 10-13-49."

Consider, too, what I believe are the last words he ever spoke to me, three months before he died. For a couple of days, I'd been visiting the nursing home for a dutiful ninety minutes and listening to his mutterings about my mother and to his affable speculations about certain tiny objects that he persisted in seeing on the sleeves of his sweater and the knees of his pants. He was no different when I dropped by on my last morning, no different when I wheeled him back to his room and told him I was heading out of town. But then he raised his face toward mine and—again, out of nowhere, his voice was clear and strong—he said, "Thank you for coming. I appreciate your taking the time to see me."

Set phrases of courtesy? A window on his fundamental self? I seem to have little choice about which version to believe.

In relying on my mother's letters to reconstruct my father's disintegration, I feel the shadow of the undocumented years after 1992, when she and I talked on the phone at greater length and ceased to write all but the briefest notes. Plato's description of writing, in the Phaedrus, as a "crutch of memory" seems to me fully accurate: I couldn't tell a clear story of my father without those letters. But, where Plato laments the decline of the oral tradition and the atrophy of memory which writing induces, I at the other end of the Age of the Written Word am impressed by the sturdiness and reliability of words on paper. My mother's letters are truer and more complete than my self-absorbed and biased memories; she's more alive to me in the written phrase "he NEEDS distractions!" than in hours of videotape or stacks of pictures of her.

The will to record indelibly, to set down stories in permanent words, seems to me akin to the conviction that we are larger than our biologies. I wonder if our current cultural susceptibility to the charms of materialism—our increasing
willingness to see psychology as chemical, identity as genetic, and behavior as the product of bygone exigencies of human evolution—isn't intimately related to the postmodern resurgence of the oral and the eclipse of the written: our incessant telephoning, our ephemeral E-mailing, our steadfast devotion to the flickering tube.

Have I mentioned that my father, too, wrote letters? Usually typewritten, usually prefaced with an apology for misspellings, they came much less frequently than my mother's. One of the last is from December, 1987:

This time of the year is always difficult for me. I'm ill at ease with all the gift-giving, as I would love to get things for people but lack the imagination to get the right things. I dread the shopping for things that are the wrong size or the wrong color or something not needed, and anticipate the problems of returning or exchanging. I like to buy tools, but Bob pointed out a problem with this category, when for some occasion I gave him a nice little hammer with good balance, and his comment was that this was the second or third hammer and I don't need any more, thank you. And then there is the problem of gifts for your mother. She is so sentimental that it hurts me not to get her something nice, but she has access to my checking account with no restrictions. I have told her to buy something for herself, and say it is from me, so she can compete with the after-Christmas comment: "See what I got from my husband!" But she won't participate in that fraud. So I suffer through the season.

In 1989, as his powers of concentration waned with his growing "nervousness & depression," my father stopped writing letters altogether. My mother and I were therefore amazed to find, in the same drawer in which he'd left those addresses and birth dates, an unsent letter dated January 22, 1993-unimaginably late, a matter of weeks before his final breakdown. The letter was in an envelope addressed to my nephew Nick, who, at age six, had just begun to write letters himself. Possibly my father was ashamed to send a letter that he knew wasn't fully coherent; more likely, given the state of his hippocampal health, he simply forgot. The letter, which for me has become an emblem of invisibly heroic exertions of the will, is written in a tiny pencilled script that keeps veering away from the horizontal:

Dear Nick, We got your letter a couple days ago and were pleased to see how well you were doing in school, particularly in math. It is important to write well, as the ability to exchange ideas will govern the use that one country can make of another country's ideas. Most of your nearest relatives are good writers, and thereby took the load off me. I should have learned better how to write, but it is so easy to say, Let Mom do it. I know that my writing will not be easy to read, but I have a problem with the nerves in my legs and tremors in my hands. In looking at what I have written, I expect you will have difficulty to understand, but with a little luck, I may keep up with you. We have had a change in the weather from cold and wet to dry with fair blue skies. I hope it stays this way. Keep up the good work.

Love, Grandpa P.S. Thank you for the gifts.

My father's heart and lungs were very strong, and my mother was bracing herself for two or three more years of endgame when, one day in April, 1995, he stopped eating. Maybe he was having trouble swallowing, or maybe, with his remaining shreds of will, he'd resolved to put an end to his unwanted second childhood.

His blood pressure was seventy over palpable when I flew into town. Again, my mother took me straight to the nursing home from the airport. I found him curled up on his side under a thin sheet, breathing shallowly, his eyes shut loosely. His muscle had wasted away, but his face was smooth and calm and almost entirely free of wrinkles, and his hands, which had changed not at all, seemed curiously large in comparison to the rest of him. There's no way to know if he recognized my voice, but within minutes of my arrival his blood pressure climbed to 120/90. I worried then, worry even now, that I made things harder for him by arriving: that he'd reached the point of being ready to die but was ashamed to perform such a private or disappointing act in front of one of his sons.

My mother and I settled into a rhythm of watching and waiting, one of us sleeping while the other sat in vigil. Hour after hour, my father lay unmoving and worked his way toward death; but when he yawned, the yawn was his. And his body, wasted though it was, was likewise still radiantly his. Even as the surviving parts of his self grew ever smaller and more fragmented, I persisted in seeing a whole. I still loved, specifically and individually, the man who was yawning in
that bed. And how could I not fashion stories out of that love-stories of a man whose will remained intact enough to avert his face when I tried to clear his mouth out with a moist foam swab? I'll go to my own grave insisting that my father was determined to die and to die, as best he could, on his own terms.

We, for our part, were determined that he not be alone when he died. Maybe this was exactly wrong-maybe all he was waiting for was to be left alone. Nevertheless, on my sixth night in town I stayed up and read a light novel cover to cover while he lay and breathed and loosed his great yawns. A nurse came by, listened to his lungs, and told me he must never have been a smoker. She suggested that I go home to sleep, and she offered to send in a particular nurse from the floor below to visit him. Evidently, the nursing home had a resident angel of death with a special gift for persuading the nearly dead, after their relatives had left for the night, that it was O.K. for them to die. I declined the nurse's offer and performed this service myself. I leaned over my father, who smelled faintly of acetic acid but was otherwise clean and warm. Identifying myself, I told him that whatever he needed to do now was fine by me, he should let go and do it.

Late that afternoon, a big early-summer St. Louis wind kicked up. I was scrambling eggs when my mother called from the nursing home and told me to hurry over. I don't know why I thought I had plenty of time, but I ate the eggs with some toast before I left, and in the nursing-home parking lot I sat in the car and turned up the radio, which was playing the Blues Traveler song that was all the rage that season. No song has ever made me happier. The great white oaks all around the nursing home were swaying and turning pale in the big wind. I felt as though I might fly away with happiness.

And still he didn't die. The storm hit the nursing home in the middle of the evening, knocking out all but the emergency lighting, and my mother and I sat in the dark. I don't like to remember how impatient I was for my father's breathing to stop, how ready to be free of him I was. I don't like to imagine what he was feeling as he lay there, what dim or vivid sensory or emotional forms his struggle took inside his head. But I also don't like to believe that there was nothing.

Toward ten o'clock, my mother and I were conferring with a nurse in the doorway of his room, not long after the lights came back on, when I noticed that he was drawing his hands up toward his throat. I said, "I think something is happening." It was agonal breathing: his chin rising to draw air into his lungs after his heart had stopped beating. He seemed to be nodding very slowly and deeply in the affirmative. And then nothing.

After we'd kissed him goodbye and signed the forms that authorized the brain autopsy, my mother sat down in our kitchen and uncharacteristically accepted my offer of undiluted Jack Daniel's. "I see now," she said, "that when you're dead you're really dead." This was true enough. But, in the slow-motion way of Alzheimer's, my father wasn't much deader now than he'd been two hours or two weeks or two months ago. We'd simply lost the last of the parts out of which we could fashion a living whole. There would be no new memories of him. The only stories we could tell now were the ones we already had.