

Also by David Shenk

*The End of Patience*  
*Data Smog*

# THE FORGETTING

Understanding Alzheimer's:  
A Biography of a Disease



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LEAR: Does any here know me? This is not Lear.

Does Lear walk thus, speak thus? Where are his eyes?

Either his notion weakens, his discernings

Are lethargied—Ha! Waking? 'Tis not so.

Who is it that can tell me who I am?

FOOL: Lear's shadow.

—William Shakespeare, *King Lear*

## PREFACE



It is easy to forget just how much we need to remember in order to do the simplest things. We don't think of ourselves as having to remember our own names, or where we live, or how to eat or read. And yet, memory—all the skills and impressions we so carefully acquired in the past—informs much of what we do. We know how to play a game when we know the rules; and knowing the rules means not having to bother to remember what they are. It is always a sign of success when we can do things without thinking; when, for example, we can read without having to go back over the alphabet. And we call this second nature, presumably, because we think of natural things, such as recognising your mother's face, or knowing where to sleep as virtually automatic. It is only when things begin to go wrong that we begin to notice just what it is we have been taking for granted. Our incompetence is a revelation.

\* \* \*

It is forgetting—absurdly, perhaps, as this remarkable book shows—that reminds us so vividly about the provenance of memory (we talk of forgetting ourselves, but not of remembering ourselves). Alzheimer's as a disease—and as a disease we should remember that it is as natural as the lives it so insidiously disrupts—reveals just how unforgiving forgetting can be. And just how dependent we are on our memory: and so, how dependent we are on others when we lose it. Impaired memory sabotages self-reliance. Other people have to do our remembering for us. Adults who begin to lose their memory as they age, like infants before they have acquired memories, cannot conceal their need for other people. With the advent of Alzheimer's we have to face the fact of there being, for many people, an adult infancy. That we will no longer be able to conceive of our lives as a journey from utter dependence to relative independence; but rather as a series of intense and mostly unchosen involvements with other people. It is the quieter implication of this startling book that the new long-term dependence of the old who have Alzheimer's—and because there are, and will be, greater numbers of older people than ever before: and therefore more people with the disease—will radically change our notions of looking after people, and our assumptions about independence. If looking after each other is one of the best things we do, looking after people with Alzheimer's makes it plain that it can also be the hardest thing we do. The fact that we find it so hard may be more of a problem than the disease itself. What we do willingly for the young we do grudgingly for the old. It has become one of the basic assumptions of our culture that we should grow out of the need to be looked after—as though the vulnerability of our bodies is itself a disease. *The Forgetting* thus reminds us of so much more than the epidemic it so tellingly documents.

\* \* \*

As a “biography of a disease” *The Forgetting* is inevitably a story of ravaged lives; and the brief accounts by sufferers and their carers have a heartbreaking immediacy. But Shenk never shirks the fact that, when it comes to Alzheimer's, to be forewarned is not to be forearmed. Indeed *The Forgetting* is itself so heartening because it tells us the facts, as stark as they are, without shying away from the cost in human terms. In this book you will find the most shocking and pertinent statistics—the life-expectancy in modern Western societies, the sheer number of older people and what proportion of the population they now are, the percentage of people suffering from, or likely to suffer from Alzheimer's, and the cost of treating and caring for those who suffer from the disease. But you will also find a web of stories that illuminate the harsher knowledge we now seem to have of this daunting disease. And also an unwillingness on the author's part to entrust the disease too entirely to the scientists. Shenk believes that our need for comfort and inspiration is every bit as urgent as our need for truth. He doesn't want the facts of life without the romance of hope. He doesn't want knowledge for its own sake, but for ours.

So there is in this book the history of the discovery, of the gradual recognition, of this disease and of the contending scientific explanations for it. Stories, that is to say, of the inspired ingenuity of scientists; and, of course, of careerism and financial opportunism (science as a democratic and disinterested pursuit is one of the book's more dismaying casualties). And there are also astonishingly lucid accounts, in the best tradition of so-called popular science, of how the disease itself works; despite the havoc it wreaks, one can't help but be struck by the sheer force and ingenuity of the disease process as it works its way through the

brain. It is part of Shenk's subtlety as a writer to be as eloquently awestruck by the intricate competencies of the brain, as he is by the (so far) unstoppable drive and resilience of the disease. Nature degenerates as inventively as it generates. Disease is, as it were, a worthy antagonist.

Like most popular science books, *The Forgetting* wants us to be impressed by the way nature works; unlike most popular science books it is unusually mindful of what might happen to us—of what we might begin to feel—if we stopped being quite so impressed. It is perhaps our greatest gift to be able to see the wonder of nature where we might only be seeing its horror. Is it possible, to write a book about Alzheimer's that leaves us with any kind of hope? What Shenk suggests is that Alzheimer's—as *the* modern disease that, apart from cancer, haunts our lives—can help us revise our very sense of ourselves. Either a cure will be found—and *The Forgetting* has its inevitable (and reassuring) cast of optimistic scientists—or many of us will have to grow up with the knowledge that aging will involve the gradual dismantling of our memories, and a regression to virtual infancy. Instead of growing out of dependence we will have to grow into it. And some of those who don't have the disease will have to become dependable in new ways. So what exactly is there to look forward to?

There is, Shenk proposes, an opportunity in our acknowledging a new-found vulnerability. The devastation of Alzheimer's has mobilised resources—scientific, communal and individual resources—that we would never have known about. And as a disease of remembering it compels us to reconsider our relationship to time; Alzheimer's, as one of the heroic sufferers Shenk quotes, is about living in (and so, for) the moment. We are what we can make out of what we have to live with. In the age of information

technology we have discovered the pathologies of memory. Alzheimer's, Shenk says, "is not only a disease, but also a prism through which we can view life in ways not normally available to us". It is part of a more realistically humane natural history to think of diseases as new ways of life: to describe illness, however catastrophic, as part of ordinary life. Out of fear of mortality we have idealised health and youth and competence. *The Forgetting* reminds us, among many other things, that there is more to life than all that.

Adam Phillips, 2001

*Chapter I*

I HAVE LOST MYSELF



A healthy, mature human brain is roughly the size and shape of two adult fists, closed and pressed together at the knuckles. Weighing three pounds, it consists mainly of about a hundred billion nerve cells—neurons—linked to one another in about one hundred *trillion* separate pathways. It is by far the most complicated system known to exist in nature or civilization, a control center for the coordination of breathing, swallowing, pressure, pain, fear, arousal, sensory perception, muscular movement, abstract thought, identity, mood, and a varied suite of memories in a symphony that is partly predetermined and partly adaptable on the fly. The brain is so ridiculously complex, in fact, that in considering it in any depth one can only reasonably wonder why it works so well so much of the time.

Mostly, we don't think about it at all. We simply take this nearly silent, ludicrously powerful electrochemical engine for

granted. We feed it, try not to smash it too hard against walls or windshields, and let it work its magic for us.

Only when it begins to fail in some way, only then are we surprised, devastated, and in awe.

On November 25, 1901, a fifty-one-year-old woman with no personal or family history of mental illness was admitted to a psychiatric hospital in Frankfurt, Germany, by her husband, who could no longer ignore or hide quirks and lapses that had overtaken her in recent months. First there were unexplainable bursts of anger, and then a strange series of memory problems. She became increasingly unable to locate things in her own home and began to make surprising mistakes in the kitchen. By the time she arrived at Städtische Irrenanstalt, the Frankfurt Hospital for the Mentally Ill and Epileptics, her condition was as severe as it was curious. The attending doctor, senior physician Alois Alzheimer, began the new file with these notes in the old German Sütterlin script.

She sits on the bed with a helpless expression.

"What is your name?"

*Auguste.*

"Last name?"

*Auguste.*

"What is your husband's name?"

*Auguste, I think.*

"How long have you been here?"

(She seems to be trying to remember.)

*Three weeks.*

It was her second day in the hospital. Dr. Alzheimer, a thirty-seven-year-old neuropathologist and clinician from the small Bavarian village of Markbreit-am-Main, observed in his new patient a remarkable cluster of symptoms: severe disorientation, reduced comprehension, aphasia (language impairment), paranoia, hallucinations, and a short-term memory so incapacitated that when he spoke her full-name, *Frau Auguste D*———, and asked her to write it down, the patient got only as far as "Frau" before needing the doctor to repeat the rest.

He spoke her name again. She wrote "Augu" and again stopped.

When Alzheimer prompted her a third time, she was able to write her entire first name and the initial "D" before finally giving up, telling the doctor, "I have lost myself."

Her condition did not improve. It became apparent that there was nothing that anyone at this or any other hospital could do for Frau D. except to insure her safety and try to keep her as clean and comfortable as possible. Over the next four and a half years, she became increasingly disoriented, delusional, and incoherent. She was often hostile.

"Her gestures showed a complete helplessness," Alzheimer later noted in a published report. "She was disoriented as to time and place. From time to time she would state that she did not understand anything, that she felt confused and totally lost. Sometimes she considered the coming of the doctor as an official visit and apologized for not having finished her work, but other times she would start to yell out of the fear that the doctor wanted to operate on her [or] damage her woman's honor. From time to time she was completely delirious, dragging her blankets and sheets to and fro, calling for her husband and daughter, and seeming to have

auditory hallucinations. Often she would scream for hours and hours in a horrible voice.”

By November 1904, three and a half years into her illness, Auguste D. was bedridden, incontinent, and largely immobile. Occasionally, she busied herself with her bed clothes. Notes from October 1905 indicate that she had become permanently curled up in a fetal position, with her knees drawn up to her chest, muttering but unable to speak, and requiring assistance to be fed.

What was this strange disease that would take an otherwise healthy middle-aged woman and slowly—very slowly, as measured against most disease models—peel away, layer by layer, her ability to remember, to communicate her thoughts and finally to understand the world around her? What most struck Alzheimer, an experienced diagnostician, was that this condition could not fit neatly into any of the standard psychiatric boxes. The symptoms of Auguste D. did not present themselves as a case of acute delirium or the consequence of a stroke; both would have come on more suddenly. Nor was this the general paresis—mood changes, hyperactive reflexes, hallucinations—that can set in during the late stages of syphilis. She was clearly not a victim of dementia praecox (what we now call schizophrenia), or Parkinson’s palsy, or Friedreich’s ataxia, or Huntington’s disease, or Korsakoff’s syndrome, or any of the other well-recognized neurological disorders of the day, disorders that Alzheimer routinely treated in his ward. One of the fundamental elements of diagnostic medicine has always been the exercise of exclusion, to systematically rule out whatever can be ruled out and then see what possibilities are left standing. But Alzheimer had nothing left.

What the fifty-one-year-old Auguste D.’s condition did strongly evoke was a well-known ailment among the elderly: a sharp unraveling of memory and mind that had, for more than five thousand years, been accepted by doctors and philosophers as a routine consequence of aging.

History is stacked with colorful, poignant accounts of the elderly behaving in strange ways before they die, losing connection with their memories and the world around them, making rash decisions, acting with the impetuosity and irresponsibility of children. Plato insisted that those suffering from “the influence of extreme old age” should be excused from the commission of the crimes of sacrilege, treachery, and treason. Cicero lamented the folly of “frivolous” old men. Homer, Aristotle, Maimonides, Chaucer, Thackeray, Boswell, Pope, and Swift all wrote of a distressing feebleness of mind that infected those of advancing years.

“Old age,” wrote Roger Bacon, “is the home of forgetfulness.”

Known as *morosis* in Greek, *oblivio* and *dementia* in Latin, *dotage* in Middle English, *démence* in French, and *fatuity* in eighteenth-century English, the condition was definitively termed *senile dementia* in 1838 by the French psychiatrist Jean Étienne Esquirol. In a depiction any doctor or caregiver would recognize today, Esquirol wrote: “Senile dementia is established slowly. It commences with enfeeblement of memory, particularly the memory of recent impressions.”

But that was *senile* dementia. What was this? Alois Alzheimer wanted to know. Why did a fifty-one-year-old appear to be going senile? How could Auguste D. be suffering from the influence of extreme old age?





We are the sum of our memories. Everything we know, everything we perceive, every movement we make is shaped by them. "The truth is," Friedrich Nietzsche wrote, "that, in the process by which the human being, in thinking, reflecting, comparing, separating, and combining . . . inside that surrounding misty cloud a bright gleaming beam of light arises, only then, through the power of using the past for living and making history out of what has happened, does a person first become a person."

The Austrian psychiatrist Viktor Frankl made much the same point in *Man's Search for Meaning*, his memoir of experiences as a concentration camp inmate. Frankl recalled trying to lift the spirits of his fellow camp inmates on an especially awful day in Dachau: "I did not only talk of the future and the veil which was drawn over it. I also mentioned the past; all its joys, and how its light shone even in the present darkness. [I quoted] a poet . . . who had written, *Was Du erlebst, kann keine Macht der Welt Dir rauben*. (What you have experienced, no power on earth can take from you.) Not only our experiences, but all we have done, whatever great thoughts we may have had and all we have suffered, all this is not lost, though it is past; we have brought it into being. Having been is a kind of being, and perhaps the surest kind."

Emerson was also fascinated by memory—how it worked, why it failed, the ways it shaped human consciousness. Memory, he offered about a decade or so before his own troubles first appeared, is "the cement, the bitumen, the matrix in which the other faculties are embedded . . . without it all life and thought were an unrelated succession." While he constructed an elaborate external

memory system in topical notebooks, filling thousands of pages of facts and observations that were intricately cross-referenced and indexed, Emerson was also known for his own keen internal memory. He could recite by heart all of Milton's "Lycidas" and much of Wordsworth, and made it a regular practice to recite poetry to his children on their walks. His journal entries depict an enchantment with the memory feats of others.

He kept a list:

- Frederic the Great knew every bottle in his cellar.
- Magliabecchi wrote off his book from memory.
- Seneca could say 2,000 words in one hearing.
- L. Scipio knew the name of every man in Rome.
- Judge Parsons knew all his dockets next year.
- Themistocles knew the names of all the Athenians.

"We estimate a man by how much he remembers," Emerson wrote.

Ronald Reagan was never particularly admired for his memory. But in the late 1980s and early '90s, he slowly began to lose his grasp on ordinary function. In 1992, three years after leaving the White House, Reagan's forgetting became impossible to ignore. He was eighty-one.

Both his mother and older brother had experienced senility, and he had demonstrated a mild forgetfulness in the late years of his presidency. Like many people who eventually suffer from the disease, Reagan may have had an inkling for some time of what

was to come. In his stable of disarming jokes were several about memory troubles afflicting the elderly. He shared one at a 1985 dinner honoring Senator Russell Long.

An elderly couple was getting ready for bed one night, Reagan told the crowd. The wife turned to her husband and said, "I'm just so hungry for ice cream and there isn't any in the house."

"I'll get you some," her husband offered.

"You're a dear," she said. "Vanilla with chocolate sauce. Write it down—you'll forget."

"I won't forget," he said.

"With whipped cream on top."

"Vanilla with chocolate sauce and whipped cream on top," he repeated.

"And a cherry," she said.

"And a cherry on top."

"Please write it down," she said. "I know you'll forget."

"I won't forget," he insisted. "Vanilla with chocolate sauce, whipped cream, and a cherry on top."

The husband went off and returned after a while with a paper bag, which he handed to his wife in bed. She opened up the bag, and pulled out a ham sandwich.

"I told you to write it down," she said. "You forgot the mustard."

It seems clear enough that Reagan was increasingly bothered by personal memory lapses. In a regular White House checkup late in his second term, the President began by joking to his doctor, "I have three things that I want to tell you today. The first is that I seem to be having a little problem with my memory. I cannot remember the other two."

Did Reagan have Alzheimer's disease in office? Yes and no. Without a doubt, he was on his way to getting the disease, which develops over many years. But it is equally clear that there was not yet nearly enough decline in function to support even a tentative diagnosis. Reagan's mind was well within the realm of normal functioning. Even if his doctors had been looking intently for Alzheimer's, it is still likely that they would not have been able to detect the disease-in-progress. A slight deterioration of memory is so common among the elderly that even today it is considered to be a natural (if unwelcome) consequence of aging. About a third to a half of all human beings experience some mild decline in memory as they get older, taking longer to learn directions, for example, or having some difficulty recalling names or numbers.

Alzheimer's disease overtakes a person very gradually, and for a while can be indistinguishable from such mild memory loss. But eventually the forgetting reaches the stage where it is quite distinct from an absentminded loss of one's glasses or keys. Fleeting moments of almost total confusion seize a person who is otherwise entirely healthy and lucid. Suddenly, on a routine drive home from work, an intersection he has seen a thousand times is now totally unfamiliar. Or he is asking about when his son is coming back from his vacation, and his wife says: "What do you mean? We both spoke to him last night." Or he is paying the check after a perfectly pleasant night out and it's the strangest thing, but he just cannot calculate the 20 percent tip.

The first few slips get chalked up to anxiety or a lousy night's sleep or a bad cold. But how to consider these incidents of disorientation and confusion when they begin to occur with some frequency? What begin as isolated incidents start to mount and soon

become impossible to ignore. In fact, they are not incidents; collectively, they are signs of a degenerative condition. Your brain is under attack. Months and years go by. Now you are losing your balance. Now you can no longer make sense of an analog clock. Now you cannot find the words to complain about your food. Now your handsome young husband has disappeared and a strange elderly man has taken his place. Why is someone taking your clothes off and pouring warm water over you? How long have you been lying in this strange bed?

By 1992, the signs of Reagan's illness were impossible to ignore. At the conclusion of a medical exam in September, as the *New York Times* would later report, Reagan looked up at his doctor of many years with an utterly blank face and said, "What am I supposed to do next?" This time, the doctor knew that something was very wrong.

Sixteen months later, in February 1994, Reagan flew back to Washington, D.C., from his retirement home in Bel Air, California, for what would turn out to be his final visit. The occasion was a dinner celebrating his own eighty-third birthday, attended by Margaret Thatcher and twenty-five hundred other friends and supporters.

Before the gala began, the former President had trouble recognizing a former Secret Service agent whom he had known well in the White House. This didn't come as a total shock to his wife, Nancy, and other close friends, but it did cause them to worry that Reagan might have problems with his speech that night.

The show went on as planned. After an introduction by Thatcher, Reagan strolled to the podium. He began to speak, then stumbled, and paused. His doctor, John Hutton, feared that Rea-

gan was about to humiliate himself. "I was holding my breath, wondering how he would get started," Hutton later recalled, "when suddenly something switched on, his voice resounded, he paused at the right places, and he was his old self."

Back at his hotel after the dinner, Reagan again slipped into his unsettling new self, turning to Nancy and saying, "Well, I've got to wait a minute. I'm not quite sure where I am." Though the diagnosis and public announcement were both months away, Reagan was already well along the sad path already trod by his mother, his brother, and by Auguste D.

The doctors who diagnosed Reagan in 1994 knew with some specificity what was happening to his brain. Portions of his cerebral cortex, the thin layer of gray matter coating the outside of his brain, were becoming steadily clouded with two separate forms of cellular debris: clumpy brown spherical *plaques* floating between the neurons, and long black stringy *tangles* choking neurons from inside their cell membranes. As those plaques and tangles spread, some neurons were losing the ability to transmit messages to one another. Levels of glucose, the brain's sole energy source, were falling precipitously, weakening cell function; neurotransmitters, the chemicals that facilitate messages between the neurons, were becoming obstructed. The tangles in some areas of the brain were getting to be so thick it was like trying to kick a football through a chain-link fence.

Ultimately, many of the neurons would die, and the brain would begin to shrink. Because the brain is highly specialized, the strangulation of each clump of neurons would restrict a very specific function—the ability to convert recent events into reliable memories, for example, or the ability to recall specific words, or to

consider basic math problems. Or, eventually, to speak at all, or recognize a loved one. Or to walk or swallow or breathe.

We know about plaques and tangles because of Auguste D. and Alois Alzheimer. After four and a half years in the hospital, Frau D. died on April 8, 1906. Her file listed the cause as “septicaemia due to decubitis”—acute blood poisoning resulting from infectious bed sores. In her last days, she had pneumonia, inflammation of the kidneys, excessive fluid in the brain, and a high fever. On the day of her death, doctors understood no more than they had on the first day she was admitted. They could say only this about Auguste D.: that a psychic disturbance had developed in the absence of epileptic fits, that the disturbance had progressed, and that death had finally intervened.

Alois Alzheimer wanted to learn more. He wanted to look at her brain.

Standing apart from most doctors at the time, Alzheimer was equally interested in both clinical and laboratory work. He was known for his tireless schedule, his devoted teaching, and his own brand of forgetfulness. An inveterate smoker, he would put a half-smoked cigar down on the table before leaning into a student’s microscope for a consultation. A few minutes later, while shuffling to the next microscope, he’d light a fresh cigar, having forgotten about the smoke already in progress. At the end of each day, twenty microscopes later, students recalled, twenty cigar stumps would be left smoldering throughout the room.

But Alzheimer did not forget about the woman who had lost herself in Frankfurt. Though he had since moved to the Royal Psy-

chiatric Clinic, in Munich, to work for the renowned psychiatrist Emil Kraepelin, he sent for Frau D.’s central nervous system as soon as she died. Her brain, brainstem, and spinal cord were gently removed from the elaborate bone casing, that flexible yet durable wrapper that allows us all to crouch, twist, and bump into things without much concern. The exposed contents were then likely wrapped in formalin-soaked towels, packed carefully in a wooden crate, and shipped by locomotive 190 miles southeast to Munich.

Imagine, now, that lifeless brain on a passenger train. A coconut-sized clump of grooved gelatinous flesh; an intricate network of prewired and self-adapting mechanisms perfected over more than a billion years of natural selection; powered by dual chemical and electrical systems, a machine as vulnerable as it is complex, designed to sacrifice durability for maximal function, to burn brightly—a human brain is 2 percent of the body’s weight but requires 20 percent of its energy consumption—at the cost of impermanence. Enormously powerful and potato-chip fragile at the same time, the brain is able to collect and retain a universe of knowledge and understanding, even wisdom, but cannot hold on to so much as a phone number once the glucose stops flowing. The train, an elementary device by comparison, can, with proper maintenance, be sustained forever. The brain, which conceived of the train and all of its mechanical cousins, cannot. It is ephemeral by design.

But there was nothing in the brain’s blueprint about this sort of thing, as far as Alzheimer could infer. This was a flaw in the design, a molecular glitch, a *disease process*, he suspected, and it was important to see what that process looked like up close.

It was also now actually possible to do this for the first time,

thanks to a whirl of European innovation. Ernst Leitz and Carl Zeiss had just invented the first distortion-free microscopes, setting a standard in optics that survives today. Franz Nissl had revolutionized tissue-staining, making various cell constituents stand out, opening up what was characterized as “a new era” in the study of brain cells and tissues. (The “Nissl method” is still in use. Nissl, a close collaborator and friend of Alois Alzheimer, became a medical school legend with his instructions on how to time the staining process. “Take the brain out,” he advised. “Put it on the desk. Spit on the floor. When the spit is dry, put the brain in alcohol.”)

Dr. Alzheimer’s assistants prepared for microscopic examination more than 250 slides from slivers of the outer lining (the meninges) of Frau D.’s brain; from the large cerebral vessels; from the frontal, parietal, and occipital areas of the cerebral cortex (locus of conscious thought); from the cerebellum (regulator of balance, coordination, gait) and the brainstem (breathing and other basic life functions); and from the spinal cord, all chemically preserved in a cocktail of 90 percent alcohol/10 percent formalin, and stained according to a half-dozen recipes of Alzheimer’s contemporaries.

Having fixed, frozen, sliced, stained, and pressed the tissue between two thin pieces of glass, Alzheimer put down his cigar and removed his pince-nez, leaned into his state-of-the-art Zeiss microscope, and peered downward. Then, at a magnification of several hundred times, he finally saw her disease.

It looked like measles, or chicken pox, of the brain. The cortex was speckled with crusty brown clumps—plaques—too many to count. They varied in size, shape, and texture and seemed to be a hodgepodge of granules and short, crooked threads, as if they were sticky magnets for microscopic trash.

The plaques were nestled in amongst the neurons, in a space normally occupied by supporting tissue known as glial cells. They were so prominent that Alzheimer could see them without any stain at all, but they showed up best in a blend of magenta red, indigo carmine, and picric acid. Alzheimer had squinted at thousands of brain slides, but he found these clumps “peculiar” and had no idea what they could be.

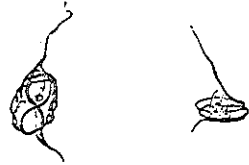
A different stain, invented just four years earlier, revealed the other strange invasion of Auguste D.’s brain. In the second and third layers of the cortex, nearly a third of the neurons had been obliterated internally, overrun with what Alzheimer called “a tangled bundle of fibrils”—weedy, menacing strands of rope bundled densely together.

The tangles were just as foreign to Alzheimer as the plaques, but at least the ingredients looked familiar. They seemed to be composed of fibrils, an ordinary component of every neuron. It was as if these mild-mannered, or “Jekyll,” fibrils had swallowed some sort of steroidal toxin and been transformed into “Hyde” fibrils, growing well out of proportion and destroying everything within their reach. Many affected neurons were missing a nucleus completely, and most of the rest of their cell contents. A good portion of the neurons in the upper cell layers of the cortex had disappeared. They just weren’t there. Alzheimer’s assistant Gaetano Perusini wrote of the neurofibrillary tangles in Frau D.’s brain:

It is impossible to give a description of all the possible pictures: there are present all the variable and twisted formations that one can imagine; at times large fibrils seem to lie only on the periphery of the cell. But on focusing untangled fibrillar agglomerations are found. Changing the focus again one has the impression that the single dark-coloured fibrils unwind into an infinite number of

thinner fibrils . . . arranged as balls of twine or half-moons or baskets.

Connecting a camera lucida to the top of the microscope, Alzheimer and Perusini both drew pictures of the tangles.



The menacing drawings perfectly convey the ghastly significance of their discovery. Here was the evidence that Auguste D. had not lost herself. Rather, her “self” was taken from her. Cell by cell, she had been strangled by unwelcome, malignant intruders.

What were they, exactly, and where did they come from?

∞

*When my kids began to say they were worrying about my memory, I said to them, “Well, I’ve never had a photographic memory, and I have a lot more on my mind now. There’s a lot more to remember with life being so complex. How can I remember everything? What do you want—total recall?” I always had an answer. I really was in denial, and it just didn’t occur to me that I had a problem. But I also knew that they weren’t totally exaggerating.*

—D.

New York, New York

∞

## Chapter 8

## BACK TO BIRTH



*Old men are children twice over.*

—ARISTOPHANES, 419 B.C.

Queens, New York: Fall 1999

The decline was sure and steady at Freund House, in Queens.

After two years in the group, Doris was now facing more severe aphasia. Her sentences were now so pockmarked with “yeah” in place of other words that it was difficult to tell what she was trying to say much of the time. Even the most productive conversations with Doris involved almost no exchange of information. Over lunch one afternoon, someone mentioned tuna fish. Doris’s eyes lit up.

“My mother had a . . . a . . .”

“A recipe?” someone offered.

“Yes . . . she . . . yeah . . . she . . .”

“She had a recipe for tuna fish salad?”

“Yes . . . wonderful.”

The thread of conversation ended there. Doris clearly had much more to say on the subject, but translating these thoughts into spoken words was no longer possible. Her world did not collapse entirely on her inability to discuss tuna fish, but to have all potential conversations restricted to a handful of words effectively extinguished her ability to communicate any real thoughts out loud. (One suspected that the intended subject of this un-conversation was not tuna fish, but Doris’s mother.)

Rachel, another veteran member of the group, was also deteriorating, and—perhaps blessedly—oblivious to the decline. At the end of one week’s session, Irving felt the need to be blunt with her. “Rachel, please talk to your son about getting a review, a medical update. I think it’s extremely important.”

“On what?”

“On the progression of your dementia.”

“Why—do you see something?”

Irving paused briefly to check his frustration. “Yes—I mentioned it to you before that we see a little more progression.”

“About remembering? Really?”

“Well, what’s happening is that there’s even a little bit more of the not-remembering that you’re forgetting.”

“Not remembering forgetting?”

“Not remembering that *you’re* forgetting. In the beginning, you used to come in and say, ‘Oh, I forgot.’ Now you don’t even remember in some of the cases that you forgot.”

“Oh.”

William was much more confused than before. He got lost on bathroom breaks. Greta had also deteriorated and seemed headed to soon join the middle-stage group for which she had once volunteered.

The group was collapsing. The original vision had been to cycle individual members out of the group as they progressed into the middle stages of the disease—once they were no longer “bothered enough,” in Judy’s words, to contribute. In practice, this had proven very tough to do, a lot tougher than Irving or Judy had anticipated. Whenever they tried to discuss the exit of one or another member, Irving explained, “The other members jumped on us. They were horrified. ‘He’s not hurting the group!’ they would say.”

Even as minds slipped away, the group still held a lot of meaning for these people. They didn’t want to let go of their friends, or to acknowledge decline. Shortly before the group disbanded, there was a frank discussion about the future. Or rather, there was an *attempt* by the group leaders at a frank discussion. Stefanie, another group facilitator, tried to prepare the group for what was in store. “This group is a temporary group,” she said. “Things may get worse. And you may not remember if they get worse.” She raised the possibility of the group retaining the same members, but beginning to meet for a good portion of each day instead of once weekly. This would mark a transition from *self-help* to *day care*.

The group would hear none of it. Even in their impairment, they were sharp enough to know what she was driving at. She was warning them that the early stages were coming to an end.

They weren’t ready. The group had been working on coping mechanisms for two years, but simply could not confront the wretched truth head-on. “A lot of people are worse off than me,” William protested. “For me, it hasn’t changed since I walked in the door. My wife would back me up in that.”

“That’s right,” Greta said, in effect demonstrating her own deteriorating memory and judgment. “He has improved tremendously. He can express himself much better than before.” Turning

to the issue of her own decline, Greta disputed claims that she had recently been seen walking around Freund House in a state of confusion. “That’s just crazy,” she insisted. Doris also claimed she wasn’t getting any worse.

Denial is an important part of the Alzheimer’s experience, very commonly employed as symptoms first appear, or at the time of diagnosis, or at any juncture where a truth is so horrifying that the most emotionally healthy choice is to pretend that it does not exist. The poisonous reality is pushed back into the recesses of the mind and only slowly, in small drips, is it allowed to seep back into consciousness.

It’s also customary for denial to fade away and then return again sometime later. This psychological mechanism of last resort can be invoked as often as need be, and in Freund House most of the group members now apparently needed to fall back on it again. For the time being, it didn’t matter that they had bravely faced down their disease together for two years. It didn’t matter that they had accepted their decreased functioning and voluntarily given up liberties like driving. It didn’t matter that they had brought much frustration and despair to the surface. A new awful truth was emerging that was too hard to confront. What they each had glimpsed, if only briefly before suppressing, were the *middle stages*. It wouldn’t be so long now before *they* were singing the Barney song and being escorted to the bathroom.

In effect, without anyone quite realizing it, the group had already become a middle-stage group. They no longer knew what had brought them there in the first place, could no longer examine the implications of their own deficits. Of the six of them, Arnie was the only one left still bothered enough to talk about the problems with some candor.



"I think we need to own up to the fact that change occurs," Arnie finally said to his friends in one of their last meetings together. "And in the main, these changes are not positive."

He paused for a moment. "I think I'll leave it at that for now."

Bel Air, California: Fall 1999

Ronald Reagan was also slipping well past the early stages. "Not good" was how Reagan's daughter Maureen characterized his condition in the fifth year following the diagnosis.

The mythic significance of the once "Great Communicator" now steadily unraveling was felt even by Reagan's detractors: Once the most powerful man on earth, he famously confronted the Soviet empire. Now he was caught in a humbling downward spiral, so powerless that he no longer even knew who he was. On the *Today* show, Ann Curry asked Maureen, "Does he remember being President?" She evaded the painful question.

Earlier in the illness, supporters had made much of the fact that Reagan was continuing to go to his office in downtown Los Angeles every day. He played the occasional game of golf and took casual walks in public parks, making himself accessible to passers-by.

Those visits and games were now over, and the Reagans had sold their beloved "Rancho del Cielo" mountaintop retreat. They were hunkering down for some more difficult times. As expected, Reagan's descent had progressed steadily. Friends and family watched his memory lapses become the rule rather than the exception. There was, for example, the day that former Secretary of State George Shultz visited his old boss. In the midst of a casual discussion about politics, Reagan briefly left the room with a nurse. When he re-

turned a few moments later, he took the nurse aside and pointed to Shultz. "Who is that man sitting with Nancy on the couch?" he asked quietly. "I know him. He is a very famous man."

Incidents like these drove him into further isolation. Partly out of simple courtesy to Reagan and partly due to their own personal discomfort, many of his friends stopped visiting when he started having trouble recognizing them.

Then came language stumbles. Over the course of a few years, aphasia crept steadily in and eventually took from him the ability to articulate his thoughts. He could, for a time, still read others' words out loud from a children's storybook. But then that too slipped away.

In visits just after the diagnosis, Maureen and her father would tackle large, three-hundred-piece puzzles. "He and I do jigsaw puzzles together," she said. "He loves doing that. When I was a little girl he used to tell me, 'Do the border first.' Now I sit there and say, 'Dad, do the border first.'"

When the intricate puzzles got too difficult, she brought him simpler puzzles of a hundred pieces or so; then simpler puzzles still, with farm animal scenes. Finally, even those became too challenging. In other homes all over Southern California and elsewhere, tiny children were, day by day, learning to distinguish colors and shapes, gaining in depth perception, improving their hand-eye coordination, slowly gaining confidence as their brains developed to full capacity. Here at 668 St. Cloud Drive, the former President of the United States was heading through that same developmental process in reverse.

The middle stages bring the end of ambiguity. The subtle cues that something was not quite right—so easy to miss a few years ago—

are now bright, self-reflecting signposts of decline, impossible to avoid. Conversation is now pockmarked with lost names and empty recollections. Time and dates have become fungible. Concentration wanes. The mind is now clearly ebbing.

Inside the folds of the brain, the progression is marked by a precise trail of pathology. Now the plaques and tangles have spread well beyond their starting point in the hippocampus. It is not clear how long they germinated there to begin with—*five years? twenty-five years?*—but in a rather short time they have now spread throughout the limbic system and leached into the temporal, parietal, and frontal lobes of the cerebral cortex. Throughout much of the thinking brain, gooey plaques now crowd neurons from outside the cell membranes, and knotty tangles mangle microtubule transports from inside the cells. All told, tens of millions of synapses dissolve away.

Because the structures and substructures of the brain are so highly specialized, the precise location of the neuronal loss determines what specific abilities will become impaired, and when—like a series of circuit breakers in a large house flipping off one by one:

In the very beginning, when the hippocampus begins to degrade, memory formation fails.

Then, when the nearby amygdala becomes compromised, control over primitive emotions like fear, anger, and craving is disrupted; hostile eruptions and bursts of anxiety may occur all out of proportion to events, or even out of nowhere.

From there, tangles spread outward through much of the rest of the brain, following exactly the same pathways that sensory data travel in a healthy brain. One tangled neuron leads to another tangled neuron leads to another, like a pileup of cars after an accident.

A preponderance of neurons in the brain, 80 percent, are devoted to so-called higher-order processing—finely tuned percep-

tion, analysis, comparison, recollection, anticipation, and abstraction—with the small remainder left for perceiving stimuli and behavioral response. Of the higher-order association areas, the temporal lobes, just inside from the ear on either side of the brain, are the closest to the hippocampus and therefore the next to bear the brunt of Alzheimer's. Temporal lobes are responsible for primary organization of sensory input, for processing language, and for ecstatic feelings of spiritual transcendence. A healthy temporal lobe stimulated by an electrical probe can spontaneously produce powerful religious images, along with specific memories of songs and vivid hallucinations of friends' faces. Not surprisingly, auditory and visual hallucinations are not uncommon in the middle and later stages of Alzheimer's.

Next in line are the parietal and frontal lobes. The parietal lobes, on top of the brain, extending to the rear, handle touch, vibration, pain, and spatial awareness. They enable the control of limbs and eyes, and the recognition of objects by physical contact. Damage to the sensory portions of the parietal lobe can cause *astereognosis*, the inability to understand the source or meaning of touch. The patient becomes an island, floating apart from the external world.

When tangles finally reach the frontal lobes, which help to manage the retrieval of already formed memories, identity itself begins to vanish. A lifetime of memories exists in constellations all throughout the brain, but without a reliable system of retrieval, they'll sit dormant forever. (The temporal lobe also plays a crucial role in accessing semantic—intellectual—memories.)

The frontal lobes are also where most of what we consider intelligent thought takes place. Here is where massive amounts of sensory data are brought together, integrated and analyzed, where the brain makes sense of unfolding events, contrasts them with previous expe-

rience, adapts future plans based on that contrast. Once the frontal lobes come under heavy fire, the will itself begins to unravel, and, as one Alzheimer's text puts it, "the chain of mental contents is no longer guided by a logically valid executive program." The sufferer and her family cannot continue to treat her forgetfulness as a liability that can be overcome with Post-it Notes. It now becomes the dominant force in the patient's life, a major disability.

The list of cognitive abilities that dwindle in the middle stages of the disease is difficult for a cognitively healthy person to fully comprehend, because the functions lost are so basic. Memories are erased not just of specific events (grocery shopping last night), but general concepts learned long ago (what groceries *are*). Other central competencies that wither include:

The ability to understand simple questions, instructions, gestures

The ability to follow a conversation, or even to keep track of one's own words or thoughts

The ability to place oneself in the right time of day, or the right time of year

The ability, even the desire, to plan for the future

The ability to choose one's own clothes and draw one's own bath

The ability to recognize one's friends and relatives, or even one's spouse

The capacity for awareness (In these years, the sufferer loses all awareness of his or her condition. Introspection vanishes. This is known as *anosognosia*.)

Perhaps the only practical way to understand such a catastrophic loss is to imagine oneself as a very young child who has not yet developed these abilities in the first place. "All actions of the bodie and minde are weakened and growne feeble," a physician of King Henry IV of France said of old age in 1599. "The senses are dull, the memorie lost, and the judgment failing so that they become as they were in the infancie." That same century, Erasmus suggested even more fully:

Old men are more eagerly delighted with children, and they, again, with old men. . . . For what difference between them, but that the one has more wrinkles and years upon his head than the other? Otherwise, the brightness of their hair, toothless mouth, weakness of body, love of mild, broken speech, chatting, toying, forgetfulness, inadvertency, and briefly, all other their actions agree in everything. And by how much the nearer they approach to this old age, by so much they grow backward into the likeness of children, until like them they pass from life to death, without any weariness of the one, or sense of the other.

Five hundred years later, caregivers use the same comparisons. "Not long after my [recently diagnosed] mother came to live with us, our daughter also came with her fourteen-month-old son," Daisy from Raceland, Kentucky, told fellow caregivers via the Alzheimer List. "I find that what works with him also works with Mom, and they give the same angelic smile when pleased. On the downside, there is also the same tantrum at times and stamp of the foot. What I do to safety-proof the house for the baby also works as Nana-proofing, for the most part. The same behavior-addressing works as well. Often when he is cranky, it is due to some other

influence—just like her. I have learned to read between the lines at both ends of the age spectrum. Sadly enough, he is learning to potty train at the time when my mom is losing that ability.”

In 1980, New York University neurologist Barry Reisberg realized that the Alzheimer’s-childhood analogy is not just anecdotal—that it could be measured scientifically. Reisberg was a pioneer in defining stages and substages of Alzheimer’s, trying to gain a much more precise understanding of the disease’s trajectory. The more he drilled down on the exact order of abilities lost, the more he was impressed by the comparison to child development. He began to notice that there were precise inverse relationships between stages of Alzheimer’s disease and phases of child development in the areas of cognition, coordination, language, feeding, and behavior.

He documented these observations in comparison charts. Placed side by side, the sequences of abilities gained and lost nearly perfectly mirror one another.

## CHILD DEVELOPMENT

<i>Age</i>	<i>Acquired Ability</i>
1–3 months	Can hold up head
2–4 months	Can smile
6–10 months	Can sit up without assistance
1 year	Can walk without assistance
1 year	Can speak one word
15 months	Can speak 5–6 words
2–3 years	Can control bowels
3–4.5 years	Can control urine
4 years	Can use toilet without assistance
4–5 years	Can adjust bath water temperature
4–5 years	Can put on clothes without assistance

5–7 years	Can select proper clothing for occasion or season
8–12 years	Can handle simple finances
12+ years	Can hold a job, prepare meals, etc.

## ALZHEIMER’S DISEASE

<i>Stage</i>	<i>Lost Ability</i>
1	No difficulty at all
2	Some memory trouble begins to affect job/home
3	Much difficulty maintaining job performance
4	Can no longer hold a job, prepare meals, handle personal finances, etc.
5	Can no longer select proper clothing for occasion or season
6a	Can no longer put on clothes properly
6b	Can no longer adjust bath water temperature
6c	Can no longer use toilet without assistance
6d	Urinary incontinence
6e	Fecal incontinence
7a	Speech now limited to six or so words per day
7b	Speech now limited to one word per day
7c	Can no longer walk without assistance
7d	Can no longer sit up without assistance
7e	Can no longer smile
7f	Can no longer hold up head

In neurological exams, there were similarly precise inverse relationships in EEG activity, brain glucose metabolism, and neurologic reflexes. The only possible conclusion Reisberg could draw was that, like the winding and unwinding of a giant ball of string, Alzheimer’s unravels the brain almost exactly in the reverse order as it develops

from birth. Clearly, the phenomenon warranted more formal study, and a name. Reisberg called it “retrogenesis”—*back to birth*.

Retrogenesis is not a perfect reversal, of course—not literally the unwiring of the brain, neuron by neuron, according to some bizarre genetic instruction booklet. But the deconstruction is remarkably similar to the construction. What researchers realized in delving further into this comparison was that Alzheimer’s degeneration followed the opposite pattern of brain *myelinization*—the insulation of nerve axons with a white myelin sheath in order to boost the strength of their signals.

Imagine a house thoroughly wired for electricity and phone use, but without any wire insulation—all the unprotected copper wires wrapped up together and touching one another. Infants are born with billions of neurons but almost no myelin insulation protecting these neurons, rendering them virtually useless. As neurons in various regions of the brain become insulated during child development, generating the famous “white matter” of the brain, these regions are *brought online*, made effective.

We know much about child brain development, thanks to J. L. Conel, a Boston neuropathologist who in 1939 began painstakingly dissecting the brains of deceased children. Over nearly thirty years, he examined the cerebral cortex from brains aged one month, three months, six months, fifteen months, two years, four years, and six years.

What he discovered comported with every parent’s experience of their growing child: The first neurons to gain myelin insulation are in the primary motor area, enabling gross movements of the hands, arms, upper trunk, and legs. Next come the primary sensory area neurons in the parietal lobe, bringing gross touch sensations online. After that comes some development of the occipital

lobe for visual acuity, followed by the temporal lobe for auditory processing. Gradually, the association areas are then formed, allowing the brain to make more and more sense of the perceptions being registered. Symbolic processing areas then begin to develop slowly, enabling language. Eventually the frontal cortex matures, enabling concentration, abstract thought, and the ability to plan.

One of the very last structures in the brain to be covered in protective myelin is the hippocampus, making it one of the last places to work effectively. This is why children generally don’t have any permanent memories prior to age three (although the amygdala can store some very early emotional memories).

The reverse myelinization process of Alzheimer’s begins with the most recent and least-myelinated brain region—the hippocampus. From there it moves to the next least-myelinated, and so on. In this one respect, at least, the disease process makes sense. It has its own logic.

For better or worse, the strange notion of reverse childhood turns out to be the best map we have to understand the terrain of Alzheimer’s. Think of a teenager you know today and try to imagine her rapid development suddenly halting and beginning to reverse course at roughly the same developmental pace. Over the next twelve years or so, she loses everything she has gained, slowly and steadily.

First, she begins to lose her sense of humor and fashion sense. Now, watch her ambitions become less and less pronounced; then begin to peel away what she has learned from school and parents and peers and television over the last couple of years. Her sense of the world and her place in it fades away. Week by week she be-

comes not more but less articulate, less independent. She loses her Dairy Queen job because she has forgotten what "ice cream" and "cone" mean, and cannot add very well. As time ticks forward but seems to be going backward, she is now having a hard time picking out her own clothes; most of what she is saying you can no longer understand, and vice versa.

Further imagine your backwards teenager traversing her way back to infancy, to her very first day of birth, her first breath, and you have a surprisingly good grasp of the unraveling of mind, soul, and body that Alzheimer's inflicts on a person. Every skill, feeling, and fact that the patient has learned slowly, satisfyingly, is being steadily erased as if by some sort of cosmic punishment.

The child analogy understandably rankles many caregivers. They are deeply offended at the suggestion that their mother or father or husband or wife is now to be regarded as a mere child. It feels like the ultimate insult one could inflict on someone. Not yet fully formed, children are regarded as incomplete persons. We love them, of course, and recognize them as human beings, but we do not fully trust them. We assume a certain responsibility and even moral superiority over them. To assume this same posture toward a parent or grandparent who has stood for a lifetime in a position of moral authority is a sad and sour thing. It is tragic and demoralizing to suddenly strip our esteemed elders of their authority and reposition them as untrustworthy and intellectually inferior.

But the comparison is a valid, and even necessary, one to make. Here is an instance where scientists fighting disease and caregivers trying to make peace with a human tragedy can come to some common ground: the science of retrogenesis can help caregivers forge a new understanding and appreciation of what their loved

ones are going through. Caregivers like Daisy from *Raceland* find the prism of second childhood helps ease both their chores and psychological strain. By viewing their loved ones as reverting back to childhood abilities and mentalities, caregivers can establish a more humane formula for their care. Whether or not it feels demeaning, retrogenesis can be *instructive*.

As reverse childhood came to seem more and more medically relevant, Alzheimer's researchers in the 1990s began dredging up everything known about developmental biology and psychology to test it for the possible application to their field. Colleagues of Reisberg, for instance, decided to test on severely demented patients a specially modified version of the Ordinal Scales of Psychological Development (OSPD), a test originally designed for infants and toddlers and based on Jean Piaget's theories of development.

This kind of ultra-basic testing had never been done before on Alzheimer's victims. The testers stripped down the OSPD so that it required no vocal abilities at all. They designed it to measure five rudimentary skills:

1. *Visual pursuit and object permanence.* Can the patient keep track of an object moving through an arc of 180 degrees?
2. *Means-ends.* Can the patient reach out for an object, causing an event to occur?
3. *Causality.* Does the patient react to a spectacle with an expression of understanding, such as a smile or frown?
4. *Spatial relations.* Can the patient adjust her vision between two objects?

5. *Schemes*. Can the patient visually inspect an object in her hands?

The experiment worked beautifully. Using criteria initially crafted to measure infant development, the researchers found what they called “residual cognitive capacities” in advanced-stage Alzheimer’s patients who had previously been considered untestable.

The implications of this discovery are enormous for the development of caregiving strategies for middle and late-stage Alzheimer’s patients. With new layers of understanding what patients are capable of and what they are no longer capable of at any specific stage of the disease, caregivers can be much more *prepared*. They can train themselves, in effect, to be competent reverse parents—not a skill that comes naturally.

If an Alzheimer’s sufferer, for example, has progressed to the point where he is trying to put on an undershirt over a sweater, it now could be easily discerned that he has slipped into stage 6a of Alzheimer’s, which, via retrogenesis, can be reasonably correlated to age four. Knowing that, one can also infer that the patient has now slid into what Piaget called the “Preoperational” stage. He is still able to represent reality through symbols (to count on his fingers, for example), but he is no longer able to rely on a solid foundation of logic (to understand the importance of going to bed early if he has to get up early the next day). He is also on the cusp of losing the sense that his point of view is distinct from that of others.

Properly utilized, the lens of retrogenesis can allow caregivers to enter the world of Alzheimer’s disease with a broad new understanding. Caregivers can hone a sense that something coherent is happening, rather than what looks to the uninitiated like a random

and unintelligible breakdown. Anyone who understands childhood can grasp the basic concept of reverting to that state, of developing in reverse. It helps make Alzheimer’s caregiving a more human endeavor.

In *Max’s New Suit*, Rosemary Wells’s popular children’s book, Max the young rabbit bumbles through the task of dressing himself. His older sister Ruby tries to teach him, but Max still puts his pants on over his head and his shirt on his legs. It is written about, and for, a very young child, but will work just as well in any nursing home (where between 60 and 80 percent of the patients are suffering from dementia). The world of children’s literature turns out to be highly relevant to Alzheimer’s. In Barbara M. Joosse’s book, *Mama, Do You Love Me?*, to give another example, a little girl asks, “What if I ran away?”

“Then I would be worried,” her mother answers.

“What if I stayed away and sang with the wolves and slept in a cave?”

“Then, Dear One, I would be very sad. But still, I would love you.”

“. . . What if I turned into a polar bear, and I was the meanest bear you ever saw and I had sharp, shiny teeth, and I chased you into your tent and you cried?”

“Then I would be very surprised and very scared. But still, inside the bear, you would be you, and I would love you.”

The book is about a child exploring the boundaries of unconditional love. But in a home tainted by Alzheimer’s disease, it also comes off as a perfect parable for the anxieties of both sufferer and caregiver. The sufferer wants to know, *What will happen when I become a real burden?* The caregiver wonders how bad the wandering, stubbornness, irritability, and bursts of

snarling anger will become. As the illness progresses, she will struggle to look through the *disease* and recognize the *person* inside.

Not surprisingly, caregivers report that Alzheimer's patients in the middle and later stages find a tremendous comfort in children's books and music. They also like stuffed animals and dolls. The child's world—nurturing, safe, colorful, full of soft edges and sweet treats—is what middle-stage patients crave. "Mom enjoys car rides," says Pam from Baton Rouge, Louisiana. "It doesn't matter where we go or if we go anywhere other than drive around. She likes to look at the trees and anything green. . . . She got to the point where being in the store didn't work out too well. Now we still go but not to accomplish anything. We walk the mall and window-shop. If we go in a store it's like the Disney Store or a toy store to look at the stuffed animals. We look at the plants and decorations. We get ice cream."

The daughter has become the mother, the mother the daughter. Catastrophic disease often alters roles, but only Alzheimer's disease can fully reverse them.



*Some days are so normal, I am guilty of thinking, "Well maybe he really isn't . . . ?" Then, to bring me back to reality, he wraps all my Tupperware in masking tape. Today, he went out to his workshop to "fix" an old LP record player, got side-tracked and ended up in the yard with a pair of clippers where he decimated my carefully cultivated rosemary bushes.*

*He was so proud of what he had done. Got rid of those weeds! Oh, well, the air was redolent with the aroma of rosemary. Rosemary is supposed to be the herb for remembrance. Maybe I should rub it in his hair.*

—M.V.  
Ft. Pierce, Florida

