

## CHAPTER FOUR: LOCKED IN

### Alzheimer's Diagnosis, Causes, Myths, and Stages

**O**n Saturday, August 16, 2008, while I was back in western

Pennsylvania for my high school reunion, I was eager to visit my special cousin—special because in addition to being my cousin and a classmate, Virginia and her husband had bought my parents' house when they moved to California in 1977. In truth, as much as I loved seeing her, I also loved being in our former house again.

My parents had built the house, hiring subcontractors for most of the work, but doing what they could on their own. I remember my mother, eight months pregnant, varnishing bedroom and closet doors just before we moved in. She gave birth to my sister Kate shortly after (at that time, prenatal toxins weren't widely discussed; fortunately, Kate wasn't harmed). The house was a 1950s-style one-story brick ranch house, centered on a large lot in a newly developed area on the single hill of our small town in western Pennsylvania. Behind our property was a wooded area and space for a large garden that I helped weed, among my other chores. I wasn't quite ten years old when we moved in, and after I went away to college eight years later, I never really lived in that house anymore. But I have so many memories of my years there.

Seeing it again was like visiting a place known from a dream—similar in form, yet different in detail. I thought it would be great to call my mother and let her know I was standing in her former kitchen. Maybe the image might spark some memory of the past where she'd spent so many years and where her children had grown up. Maybe it would make her happy to picture me there.

But no one at the senior residence knew where Mom was.

"Try calling the beauty salon," the receptionist who answered the phone suggested to me. I had my doubts because, even though the salon was just down the hall from Mom's room, she seldom had found her way there alone. This time was no exception. She wasn't there.

I tried calling my brother, but since I couldn't reach him, I became quite alarmed that something terrible may have happened to Mom, maybe even a stroke or a heart attack.

After what seemed like endless hours of calls and agonizing worry, I finally reached Michael, who explained what had happened. Mother's usual health care worker had had three days off. When a new aide without a key had come to her door, Mom didn't recognize her voice and wouldn't let her in. Unfortunately, even though August temperatures in Nevada could spike to 112

degrees outside, somehow the air conditioner in Mom's room had been turned off. Whether she'd done this herself or someone had neglected to turn it on, no one knows or will say. What I did learn was that as her room became stifling hot with each passing hour (or day?), Mom had had enough presence of mind to lie down in her underwear on the bathroom floor tiles to cool off. Not one staff member had noticed her absence for an unknown period of time and checked on her, even though she had missed meals.

When Michael found her there at three-thirty on Friday afternoon, the day before my calls, she was both dehydrated and delirious. He called paramedics who rushed her to a hospital, where an internist and cardiologist stabilized her condition; her blood pressure had soared to a systolic reading of 210. An electroencephalogram showed that she had not had a seizure. Four days later, she was still weakened but considered to be well enough to be transferred to a rehabilitation hospital.

The staff at the rehabilitation hospital wasted no time in administering some memory tests to my mother and quickly classified her as definitely having Alzheimer's disease. She was to be transferred to a one-story, locked memory-care unit, the small building alongside the large, two-story main building where she'd been living the past twenty-seven months.

Michael wrote to my sisters and me on August 26, 2008:

Mother is going to be discharged this coming Saturday. She's unfortunately going to have to change apartments to the secured unit in the back, which is locked, with a twenty-four-hour attendant. She's too confused and wandering around the rehab hospital and not safe on her own, even with a home aide visiting. Her new room will still accommodate most all of her present furniture, but some things will need to be boxed and taken out. She will be in a double room with a roommate because a private room is extremely expensive. We'll also keep a home aide coming that is on her home health policy and no further out of pocket cost; this gives her extra care and attention. The agency is going to be changed to a different one that is in the process of being evaluated.

I responded:

By "secured unit in the back" are you referring to the memory-care building? When we spoke last week, you were against Mother going there. What happened?

I'm concerned about her "wandering around

on her own.” This was never mentioned as an issue before. She barely left her room, the dining room, and the lobby. She was reluctant to try the elevator or go up the stairs even with someone to help her. When did things change, and who reported this change? Are they trying to protect themselves from their failure to care for her?

I appreciate your informing us of this possible move, but with all due respect, I'd like to have more discussion and more input. Probably you have good reasons, but I need to know more about them. In short, the thought of her moving is bad enough. To think of her having to spend the rest of her life in a room with another person is intolerable. Once again, I don't want to be challenging, but I'm questioning and needing more information. Let's all think about this together.

Michael replied on August 27:

This decision was made by the rehab hospital and their physicians. Mother actually fell out of bed last night, but no injury, thankfully. Here is the case manager's phone number. They have made the decision, not me and not the administrator where she was living. They state she's not safe and won't allow her to go back to her apartment. I tried to get her to stay where she'd been with more home aide hours, but they refused. She has a “wander bracelet” on so she won't walk out of the building. She doesn't use the walker and is still unstable, but stronger and with very poor recall. The price goes up about \$600 a month for the memory care semiprivate room. A private room there costs over \$8000 a month. All of the time.

I thanked my brother for the additional information and called the case manager as he suggested. I requested that instead of giving her cognitive tests under these conditions when she was so clearly stressed, she be returned to her studio apartment and given some time to calm down and perhaps regain her pre-accident mental abilities before being tested again. I pointed out that they were making a recommendation based on my mother's behavior in a location that was completely strange to her and where she was bound to be distressed and confused. Everything there was different—people, sounds, smells, food, even having to wear hospital gowns. I suggested it was natural for my mother to be wandering in and out

of rooms; she was disoriented and trying to find her room and her own belongings. Also, she wasn't used to sleeping in a single bed, which may be why she'd fallen out of bed the night before. I tried every argument I could think of.

Later I learned from the Fisher Center for Alzheimer's Research Foundation website that dehydration may lead to a false diagnosis of AD, a fact that was repeated at a UCSF conference I attended in March 2014. The speaker at UCSF also added that unfamiliar people, noise, lack of sleep, a strange place, and some medications can all lead to delirium and depression, and that any hospitalization is stressful, especially for individuals with dementia.<sup>12</sup> At the time, however, I simply felt their recommendation in moving Mother now was taking two giant leaps into an irreversible position that was quite possibly more extreme than she needed at her stage.

I also requested that her status where she'd been living be changed from "independent" to "needs assistance." If that had been the case, she never would have been missing because she'd have had someone on the premises to check on her and to help her with basic care such as showering and dressing. "Needs assistance" would have cost more money (although my father had left Mother with an ample amount of money and none of us would've had to cover her costs), but it would have been more secure than depending on the arrival of a visiting angel that the home health-care policy provided.

I wrote to Michael:

It may very well be that we'll have to make the decision to move her into a memory unit sometime in the future. But I strongly feel that we owe it to her to try a step up first before we do something that could really put her over the edge of sanity. The case manager told me that you have already found a new home health-care agency that will give Mom three hours a day, which is good; the last one wasn't even giving her one hour. She also said that the decision where Mom lives is up to us, her family, if we are willing to take responsibility for her safety. I for one am completely willing. In fact, I'm even willing to move her to an assisted living facility near me where she can have a private room for approximately \$5,000 a month. Please call me when you have time to talk about my idea. Also, I'll be there to see her a week from tomorrow. Please don't move Mom until we can consider all options.

Michael replied that he'd tried to get Mother moved back to her apartment but was informed by the case manager that this wasn't

an option. As he pointed out, it certainly was much easier for him if Mom could stay in her own apartment with more care because he wouldn't have to move all her furniture and personal belongings. He added that if he could get agreement for her to return, it would be great, but he'd tried and was met with denial. As he said, "I'm her son in this situation, not the doctor, and not making the decision—just trying to do the best for Mom."

I answered:

Michael, I'm sure that you're trying to do the best for Mom, not just as her son, but also because you're a doctor and are able to evaluate her present condition. I'm also trying to be an advocate for her, but obviously I don't have the most recent impressions. From what you're telling me, she has had a decline in the last two to three weeks. Whether that is the cause or the result of her bad experience with the air conditioner being turned off, we'll never know.

I was waiting to hear back from the nurse at the senior residence to see if Mother could return to her studio apartment, but she never responded to my call. I never heard one word of apology or explanation from the administration about their failure to check on Mother when she was missing at meals, although a simple check of the guest registry would have shown that she'd not been signed out. I suspect that the decision not to take her back had as much to do with their refusal to accept future responsibility as it did with the diagnosis of her condition.

Michael wrote to me:

I'd like Mom to stay in her own apartment as well but was getting an absolute "no" answer from the case manager.

I'm very concerned about Mom because she wets her pants and doesn't even know to get them changed. She did this last weekend, and they showed me photos of her scalded skin from urine burns. On top of this, falling out of bed and overall poor balance. When she went to the hospital she had bruises on her knees and ankles in varying stage of healing. This appears to have been going on for a period of time, and Mom has been hiding it.

Equating this last alarming description with the same mother who had visited us for two weeks, including our Mother's Day celebration with her, just three months earlier, was almost beyond

my ability to imagine. At that time, she'd been completely continent and had no bruises from falling, nor did she have any burns from scalding or any other causes. What kind of supervision and care had she been receiving? Could she have changed so much so rapidly? Patricia even broke her years of silence and sent me a long e-mail, urging me to "please stop debating this issue." In spite of all the letters and comments, however, I still wasn't clear who was really in charge of the decision.

Nor was I ready to accept the diagnosis of Alzheimer's disease at this point based on whatever tests the staff at the rehabilitation hospital had administered. Had they done the necessary complete blood cell count and blood analyses for levels of vitamin B<sub>12</sub>, glucose, and electrolytes recommended by the American Academy of Neurology? Had they tested thyroid and liver functions? Done depression screening? I doubted very much that they'd checked her biomarkers, although newer studies focus on establishing biomarker criteria and guidelines that will show changes in the brain, cerebrospinal fluid, and blood associated with AD before the symptoms actually appear. My notes indicate that they did perform an MRI that showed "severe atrophy," probably a reference to the bilateral temporal lobe atrophy Michael had only recently told me about, damage that would affect her in many ways. The temporal lobe, which contains the hippocampus, is one of the first brain areas to be damaged by AD. Among other losses for my mother would be the abilities to remember recent events, to recognize faces, and to understand what she hears.

Still, I was suspicious of the diagnosis for good reason. As Dr. Sam Gandy, director of the Mount Sinai Center for Cognitive Health in New York City, says, "One concern about the increased visibility and prevalence of Alzheimer's disease is that some physicians will be tempted to jump straight to that diagnosis without first having followed the 'rule out reversible causes' rule." He adds, "We must always seek to exclude treatable, reversible causes of dementia such as depression, nutritional deficiencies, endocrine disorders, and metabolic disorders before rushing into a diagnosis of Alzheimer's."<sup>13</sup>

Why was I resisting "a diagnosis of Alzheimer's" for my mother? I resisted because Alzheimer's isn't treatable or reversible, but dementia may be. Dementia is defined as a significant decline in mental ability that persists over time in two or more categories: memory loss, language, reasoning and judgment, visual perception, and ability to focus and pay attention. Dementia causes problems, it's true, but some hope exists with certain types of dementia. According to Dr. Peter Rabins, dementia can be treated and reversed in about 1 percent of cases.<sup>14</sup> Only by ruling out the following reversible or treatable causes of dementia is a diagnosis of Alzheimer's then considered to be 90 percent accurate. These include:

- hypothyroidism,
- depression,
- an operable brain tumor,
- vitamin-B<sub>12</sub> deficiencies,
- drug and alcohol abuse,
- sleep disturbances, and
- toxic reactions to either prescription or over-the-counter drugs, especially sleeping pills.

Many dementias, on the other hand, are irreversible and come from a variety of other causes, such as:

- Alzheimer's disease (accounts for about 70 percent of cases),
- vascular dementia (accounts for about 17 percent of cases),
- frontotemporal dementia,
- dementia with Lewy bodies,
- Down syndrome,
- AIDS,
- Huntington's disease,
- Parkinson's disease,
- Pick's disease,
- Creutzfeldt-Jakob disease, and
- brain disorders caused by trauma, illness, and infection.

In spite of its prevalence in this group, diagnosing Alzheimer's disease has been problematic ever since the German doctor Alois Alzheimer first reported brain abnormalities in his fifty-one-year-old female patient, Mrs. Auguste D., in 1906. Certainly, she wasn't the first person ever to show debilitating memory loss; many famous people throughout history who'd lived long lives eventually suffered with what became known as "senile dementia" because of its association with old age. But Mrs. Auguste D. was a special case that attracted widespread attention, not only because of her relatively young age, but because Dr. Alzheimer's report on her autopsy described damage he'd never before seen: shrinkage of the brain's cortex that is involved in memory, thinking, judgment, and speech. He also described "clumps," now known as amyloid plaques, and "knots" or "neurofibrillary tangles," now called "tau," throughout her brain. The publication that described his findings gave his name to the disease.

The rather pejorative term "senile," however, was still used throughout the 1940s and continued the false belief that cognitive decline was a part of normal aging caused by cerebral arteriosclerosis. Then in the 1950s, technical advances such as electron microscopes allowed researchers to study the structure of the brain and see the plaques and tangles directly related to Dr. Alzheimer's discovery a half century earlier. The term "senile" was dropped when it was recognized that younger persons from thirty to fifty years old,

like Mrs. Auguste D., could also have “Alzheimer’s disease” as it is now called. Often abbreviated and used interchangeably with AD, Alzheimer’s disease was recognized as a distinct disease and its diagnostic criteria were first outlined in the *Diagnostic and Statistical Manual of Mental Disorders* in the 1980s.

Then in 2002, a UCLA research team discovered a new way of using positron emission tomography (PET) that showed in living patients the same kind of tiny plaques and tangles Dr. Alzheimer had first seen under a microscope after his patient died. Plaques, which look something like fried eggs, are made of a protein called beta-amyloid that blocks cell-to-cell communication between neurons at the synapses and may also activate immune system cells, triggering inflammation there. Tangles are also composed of a protein, this one called tau. Tau resembles parallel strands like railroad ties that support the vital cell-transport system of nutrients within the neuron. When tau collapses into twisted neurofibrillary threads or tangles, nerve-cell death results. Today’s researchers are largely either the “baptists,” who research beta-amyloid plaques, or the “tauists,” who consider tau to be a more primary cause of Alzheimer’s, and the two groups compete for scarce research dollars.

Based on MRI imaging of memory changes in major brain regions, scientists at Columbia University Medical Center say that Alzheimer’s begins in the temporal lobe at the lateral entorhinal cortex (LEC), the gateway to the hippocampus where new learning takes place and memories of recent events are formed. It progresses eventually to other areas of the cerebral cortex, especially the parietal cortex that is involved in spatial orientation and navigation. Sensory functions of vision and smell become impaired, and personality may change. Neurons break down structurally with beta-amyloid plaques and tau tangles, and the cholinergic neurons produce less of the neurotransmitter acetylcholine so critical for learning and memory. The brain becomes riddled with holes as the four ventricle cavities filled with cerebrospinal fluid expand and the cortex shrinks in size. This is what happens, but it doesn’t explain why it happens. Several theories exist, but none so far are conclusive and incontrovertible.

One difficulty of diagnosis is that the presence of beta-amyloid plaques and/or tau neurofibrillary tangles in a PET scan is not necessarily predictive of Alzheimer’s disease. Even if both are present, an individual may have no cognitive deterioration; about one person in five receives a mistaken false positive diagnosis. Among twenty-one subjects with mild cognitive impairment whose PET scans showed plaques and tangles spread throughout several regions of the brain at the beginning of a study, only six individuals (29 percent) were diagnosed with Alzheimer’s during follow-up two years later.<sup>15</sup>

Still unknown, therefore, is whether plaques and tangles are



the cause or the effect of Alzheimer's disease. Some researchers are now looking beyond the structural damage they cause in the brain, focusing instead on the functional interaction and communication between brain regions, such as the prefrontal cortex and hippocampus, affected by the decline in neurotransmitters. Other researchers are pursuing different theories: Is AD a prion (infectious protein) disease? Or is Alzheimer's caused by a virus? Are plaques really the result of tiny proteins called oligomers that are toxic to brain cells? Does chronic inflammation destroy neurons? Or are neurons destroyed by free radicals that cause oxidative stress? Do the imperceptible ministrokes called microinfarcts that are common in older adults contribute to dementia?

With no full knowledge of how and why Alzheimer's disease begins, a number of early theories were advanced. All of these have now been relegated to the category of myths, according to the Alzheimer's Association:

- **Myth:** Memory loss is a natural part of aging.  
**Fact:** AD is a disease that causes brain cells to malfunction and die.
- **Myth:** Alzheimer's disease isn't fatal.  
**Fact:** No one survives AD.
- **Myth:** Only older people can get AD.  
**Fact:** AD can strike people as young as thirty years old.
- **Myth:** Aluminum, aspartame, flu shots, and silver dental fillings can all increase the risk of AD.  
**Fact:** None of these have been confirmed to be true.
- **Myth:** Treatments are available to stop the progression of AD.  
**Fact:** Not at this time.

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As it stands now, since a definitive diagnosis for Alzheimer's disease can't be made until autopsy, I was still not completely certain that my mother had AD at this time, especially since I'd recently spent two weeks with her and observed her behavior closely every day. But given the fact that most of the causes for reversible dementia had been ruled out in my mother's case, I had to concede that she would probably have Alzheimer's disease eventually because it's the most prevalent of the irreversible dementias, and she did have certain risk factors.<sup>16</sup>

- First, of course, was her **age**, eighty-eight years old. Alzheimer's disease is still correlated with old age—again, age doesn't cause AD, but the risk of having it increases with age. According to the Alzheimer's Association, beginning at age sixty-five, the risk of developing Alzheimer's doubles every five years. At that age, the chance of developing

dementia in one's remaining lifetime is one in twenty. Thirty-two percent of those aged eighty-five have AD; after that, the risk of developing it reaches nearly 50 percent.

- Being **female** also puts her at higher risk. Because more women are in the older age groups, and because women live longer with dementia than men do, almost two-thirds of AD patients are women. After the age of sixty-five, roughly 3.2 million women have AD, compared to 1.8 million men. In terms of percentage, past the age of seventy-one, 16 percent of women have AD; 11 percent of men do. Some researchers continue looking for a hormone effect with the decrease of estrogen after menopause, but none has been substantiated so far.

- In terms of **education and socialization**, Mother had only an eighth grade education and hadn't challenged herself intellectually. She socialized mainly with her own family. Women with higher education are 45 percent less likely to develop dementia compared to women with less education.

On the positive side, however, Mom's risks were lower because she:

- smoked rarely, if ever,
- drank little alcohol,
- maintained a healthy weight and an adequate diet,
- married, and
- had good exercise and sleep levels.

Also she did not have two other risk factors:

- Stroke or head injury
- Diabetes

Clearly, however, my mother already did have some stage of dementia (now also called "neurocognitive disorder"). My brother, a medical doctor, saw Mother's condition in terms of symptoms and a disease that needed medication. I saw her in psychological terms as a person troubled by loss of memories and cognitive impairments, but still an individual with abilities and emotions that existed in spite of those losses.

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At what point then do memory problems become dementia? There is a continuum of memory and cognitive problems that ranges from the first two stages of normal, preclinical changes called Age Associated Memory Impairment (AAMI) and Age Associated Cognitive Decline (AACD), to Mild Cognitive Impairment, and then on to stages of dementia. Many diagnostic settings use the rating scale developed in 1982 by Dr. Barry Reisberg, the Clinical Director of New York University's Aging and Dementia Research Center, to help determine the progression of neurocognitive disorder.<sup>17</sup> The stages in Reisberg's rating scale are numbered in order of increasing severity, and they may overlap. Also, not everyone who is in one of the earlier

stages will go on to develop later symptoms on the continuum. The website Alz.org has an expanded description of these stages:

- **Stage one:** No impairment

Normal function: The person does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms.

- **Stage two:** Very mild cognitive decline (affects half the population over the age of sixty-five). May be normal age-related change or very early Alzheimer's. Stage two is a critical stage when early intervention can be most effective.

- **Stage three:** Mild cognitive decline (MCI): poorer memory than usual for age, serious enough to be noticed by patient and others, but not serious enough to interfere with Activities of Daily Living or functioning independently.

MCI is considered to be a stage of transition between normal aging and mild dementia, affecting 10 to 20 percent of people age sixty-five and older. Although MCI does not always lead to dementia, up to 15 percent of those with MCI will progress to Alzheimer's disease each year, compared to 1 to 2 percent of the general population.<sup>18</sup> One out of every two people with MCI will develop AD within three or four years—but 50 percent will not.

- **Stage four:** Moderate cognitive decline (early stage Alzheimer's disease)

Some difficulty with Activities of Daily Living, such as bathing

Anxiety, depression, or agitation may be present

Trouble with trivial activities

- **Stage five:** Moderately severe cognitive decline

Needs help with Activities of Daily Living, such as dressing

First stage of obvious dementia

Problems remembering autobiographical data (address, phone number) and major life events

Family members may not be recognized

Problems with sleeping and wandering

- **Stage six:** Severe cognitive decline (middle dementia or moderate Alzheimer's)

Cannot perform basic Activities of Daily Living, including feeding

Weight loss

Noticeable personality changes

Loss of bladder and bowel control

- **Stage seven:** Very severe cognitive decline

Communication and motor impairment; may not be able to speak or walk

Totally helpless and dependent on others

May comprise 40 percent of the time living with AD

Although the above scale provides a guide, Alzheimer's disease doesn't present the same symptoms, behaviors, or progression for each individual, and stages aren't always clearly delineated until the final ones. In contrast to my mother, one of our friends, a brilliant attorney and head of a large successful law firm, moved very quickly from some symptoms of memory loss and confusion, to needing a round-the-clock caretaker at home, to full-time residential care, to being unable to recognize even his wife, all within the space of a few years. He died in his mid-seventies.

My mother at the time of her hospitalization after the air conditioning incident did not show the behavioral symptoms of irritability, anxiety, or depression sometimes seen in early stages of AD. Her symptoms were a combination of mild cognitive decline (MCI), stage three, overlapped somewhat with parts of stages four and five. Memory was her chief problem, but she could dress herself and could recognize family members. She still had basic skills that I wanted to help her maintain for as long as possible. And Alzheimer's disease was so much worse than her present condition. Memory losses due to aging, those so-called "senior moments," are mischievous kittens of forgetfulness compared to the ravenous tiger of Alzheimer's that slowly devours the brain and the very essence of selfhood. My mother's current stage was more analogous to that of a pet cat.

AD has been considered by many to be a fate worse than death. Alzheimer's disease slowly deteriorates not just memories but also one's identity and sense of self. The very processes of thinking, judgment, and problem solving disappear as brain cells stop functioning, lose connections, and die. Over time, the brain—especially the hippocampus and prefrontal cortex—shrivels and shrinks.

Although the rate of progression varies from person to person, the path is unrelenting. AD leads painfully from loss of memory to the inability to communicate with others, to a loss of basic self-help skills like eating and continence, to possible delusions or hallucinations, and even to personality changes. Gradually the person becomes bedridden and helpless, unresponsive to surroundings and unable to recognize family and loved ones. Eventually, there is susceptibility to other illnesses, pneumonia being the most common, as the motor system that governs swallowing and breathing deteriorates, leading to death. As Harry Johns, president and CEO of the Alzheimer's Association says, "Unfortunately, today there are no Alzheimer's survivors. If you have Alzheimer's disease, you either die from it or you die with it."

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Is there any wonder I resisted the diagnosis and preferred that my mother be classified with MCI, which doesn't always lead to Alzheimer's? Placing my mother in a memory-care unit among a group of Alzheimer's patients was to consign her to their same fate too soon, I thought. Nevertheless, my protests were in vain. The decision had been made. Mother was being moved to a new residence for the second time in twenty-seven months, surely a source of more disorientation, confusion, and possibly depression for her.

September 1 was four days away, and Michael and Patricia wanted Mom to be moved into the memory-care unit before the month began. Her queen-sized bed, a nightstand, a chair, a small cabinet, and a TV with stand were squeezed into her new quarters—a hospital sized room with two beds (separated by a curtain and later a partial wall) and a shared bathroom. She and her roommate also shared the one sliding-door-type closet. It had space for hanging clothes at either end and, in the middle, two shelves apiece for folded clothes. Shoes went below, and larger items like extra blankets could be stored on the shelf above. Mother's remaining wardrobe was reduced to a bare minimum; not even one warm coat was in her closet. Evidently, no one was planning to take her outside for a while. (I brought her a warm coat.)

With regard to her roommate, Patricia and I had both been wrong. Far from bonding together and becoming new friends, as my sister had thought, the two women never even spoke to one another. Nor did my mother seem to mind sharing the room with a stranger, as I'd predicted. It may have been because my mother's roommates usually spent almost all of their time in bed, sleeping.

In spite of the limited space and loss of her privacy—as well as almost everything else Mom had once owned—I tried to have a positive attitude about the possible advantages of memory care as I found them there. The staff (all but two were female) was attentive and kind. Since the number of residents varied, it was difficult to determine a resident-staff ratio, but usually there seemed to be at least thirty residents at any given time; the maximum number was forty. Almost all were elderly females; just a few were older men. Most of them probably had late-onset Alzheimer's, sometimes abbreviated as LOAD.

Two younger women in the memory-care unit had the rare early-onset form of Alzheimer's disease that strikes before the age of sixty. One of them, an attractive woman with long dark hair, perhaps in her late forties, spent long, lonely hours in an otherwise empty sitting room, staring at the moving shapes on the television. This cruel form of AD accounts for about 5 percent of Alzheimer's patients, or currently about two hundred thousand individuals; by 2050, up to sixteen million people may be afflicted with early-onset

AD. The exact cause at such a young age is still not known but is believed to be genetic.

The square building was very clean, well furnished, and attractive. A pleasant open-square atrium was in the middle of the locked building so that residents could walk outdoors there (although I never saw any of them take advantage of this), and everything else was arranged around the atrium. On the near, entry side, of the building were reception, the office, a nurses' station, and the dining room. Along the far side of the atrium were the activity area with tables and chairs, an aquarium, a kitchenette for preparing snacks, and an area for watching television. Murals painted on the walls in the activity area portrayed small scenes of the outside world, such as a florist stand, a fruit cart, and a dressmaker's shop window circa the 1940s; recreating an earlier period in their lives has been shown to make people feel and act younger in that surrounding. The patients' rooms were basically arranged on the perimeter along the sides and back of the building.

No particular odors were noticeable. Aside from at mealtime, liquids—even water—weren't available, except for juice offered with a midafternoon snack, and residents were kept in diapers, further eliminating accidents and smells. I don't know if my mother was aware of suddenly having to wear diapers now. Considering Michael's last letter to me, she needed them. Again, this was a rather abrupt, drastic change for her. My brother and his wife kept Mother supplied with those personal needs.

The food was nourishing, varied, and quite good, but the dining atmosphere was beyond dismal. One or two smaller table groups of four managed to hold an occasional conversation, but they were exceptions. One day I counted that of the eight residents at Mother's table, three of them were sleeping and four needed to be fed soft food. My mother, however, ate her meals with gusto. She began a habit of folding her napkin, sometimes with some silverware tucked inside, to carry around with her when she left the dining room. She did the same thing in restaurants, and I had to gently remove the items from her before we left the premises. I think she felt lost without having a purse to carry any longer because when I took her on outings, she often asked me where her purse was.

Best of all, there was a wonderful activity director named Marcos who led seated exercises every morning to stretch the patients' muscles and help their coordination. He devised crafts and games that he personally invited patients to join by going to their rooms and escorting them to the activities. Marcos was an excellent musician and played music from the 1930s and '40s on a keyboard every day, making it sound like a real swing band, encouraging all of the residents to sing along with him. (There is a

theory that people become imprinted to the musical genre that was popular when they were about the age of twenty, and that kind of music remains their favorite throughout life.) Even if some of the others just dozed at the activity table or slumped, often drooling, in their wheelchairs, my mother was an enthusiastic and active participant in almost all activities except bingo, especially in her favorite activity, singing along. How interesting that some part of the brain connected to music must also maintain the memory of lyrics! This could be related to the fact that hearing is the last sense to be lost. In fact, some senior residence centers form singing groups composed of their Alzheimer's patients, providing them with an enjoyable activity. Too bad there was no group at this memory-care unit. Mom remembered the words to all of the old songs, and she'd have enjoyed the sing-alongs.

Still, in spite of the level of care, the appearance of the facility, the efforts of the activity director and the visiting angel, the visits from my brother and his wife, my own visits and attempts to stimulate her involvement in the outside world by taking her for outings, my mother continued to decline cognitively in the memory-care unit. I could understand why.

Some things bothered me, even on a daylong visit. Why were the patients denied water to drink throughout the day? I could understand that there were no glasses, but could there not be paper cups available? (I made sure to bring a bottle of water with me to share with Mom after the first time I visited and found it impossible to get any water to drink for myself.) Was withholding water a means of cutting down on diaper changes? Why were activities mostly limited to the mornings? For patients who could no longer read or understand television shows, would the rest of the day not seem terribly boring? With nothing to do all day long, how would anyone stay mentally active?

Seldom did any of the residents initiate a conversation with one another, although they could be quite aggressive and argumentative if someone didn't take turns correctly when they were playing games, such as throwing a foam ball to one another while they were seated around the activity table. As their social inhibitions declined, they also took critical notice and made inappropriate comments about each other's appearances and mannerisms; several made fun of one newcomer who carried around a doll and talked to it as if it were her baby. In many ways, they had regressed to the stage of nursery school children who hadn't yet learned to interact appropriately. My mother unfortunately became one of the ones who would audibly point out odd behavior or appearance, and she wasn't always pleasant to lost souls who wandered into her room. As the years went by, Mom herself might wander into other rooms, not able to find her own.

In time, the staff sometimes referred to Mother as “the walker” because she walked around and around the quad. She’d never been one to sit around and do nothing, and walking was now her only way of staying strong and active. Or perhaps it was just something to do; maybe she missed the walks she used to take when she was allowed to go outside. When the staff requested that she use a walker for balance, she refused and hid the walker under her bed, and when she was placed in a wheelchair, she made sure she got out of it as soon as she was able. When she couldn’t sleep, the staff told me, she’d be up at night, walking. Later I learned that wandering or pacing and a change in sleep patterns were two symptoms of the moderate level of dementia. Walking aimlessly is a common sign of agitation, and when not walking, taking naps during the day because of boredom also causes wakefulness at night.

Walking was actually quite good for Mom, however. The exercise helped her circulation and breathing, giving more blood and oxygen to her brain, which improve its functioning. Walking also reduces anxiety, agitation, and restlessness. Yet no matter how long or how fast my mother walked, Alzheimer’s was stalking her and gaining ground. In the years she was in the memory unit, she could never, ever outrun it. I finally had to recognize my mother’s eventual diagnosis of Alzheimer’s disease. She was now almost eighty-nine years old.

In the memory center where she no longer had her own room, my visits with my mother were mainly day trips—one long day of morning and evening flights plus renting a car at the airport so I could continue taking my mother out to restaurants, shopping, on sightseeing drives, and to movies as long as she was able and willing to go. The first time I tried to sign her out, the office had to call Michael for his permission, which he gave. Perhaps the director was worried I was going to kidnap her after my reluctance to have her moved there. I might have tried, but I didn’t have her power of attorney, her medical records, or access to her financial accounts, so there was no way I could move Mother without my brother’s permission and cooperation. Nor could I ever bring her with us to Puerto Vallarta again. When I asked him to allow her to come with us on another vacation, Michael said her birth certificate was lost, and he wasn’t going to request a new one in order to obtain a passport that the law now required.

Generally, I went alone on my daylong visits to see Mom at the memory center, but sometimes my husband Ed went with me and we’d stay at a hotel nearby to be able to spend two days with my mother. Once, my older daughter Karen accompanied me. Later, my sister Kate and I managed our flight schedules on a few occasions in order to meet each other at the airport in Las Vegas and spend the day together with Mom.



The last movie I was ever able to take Mom to see was, ironically enough, *Mama Mia*. We went to the matinee, which happened to be a sing-along, and we were the only audience in the huge theater. Mom and I held hands, and at the song “Slipping through My Fingers,” tears rolled down my cheeks. In the song, the mother is singing to her grown daughter, who is about to leave and begin her own life. For my mother and me, the pendulum of time had swung forward, and our roles were almost the exact opposite of the ones on the screen.

I’m quite sure that as soon as I’d leave Mom and return to the airport for the flight back to San Francisco, she’d forget I’d even come to see her. But if she could be happier for just the few hours of my visit, I knew it was worth my effort to make whatever trips I could. Not only were they making her life more pleasant, they allowed me to spend precious time with her.

Because of the difficulty and expense of visiting her frequently, several times a week I called Mom in the evening for a chat before she went to bed. Patricia had suggested to Michael that he turn off Mother’s phone to save money since she wasn’t able to initiate calls. He wrote to Kate to ask our opinions, and I explained through Kate why I’d wanted Mom to keep her phone. Fortunately, the phone was never turned off. Those evening talks, sending each other hugs and kisses over the phone, were my way of tucking Mother into bed and wishing her sweet dreams. It was mainly through these evening phone calls that my mother expressed herself the most.

Sometimes when I asked her how her day had been, she’d tell me, “Oh, I was so busy all day.” Or, “I went out and did some shopping,” or something else she made up. Was she engaging in fantasy to fill her boring days? Was she inventing a story to make me feel good and hide her unhappiness? Or was her lack of stimulation causing her to imagine an alternate reality? Is this what happens to prisoners in solitary confinement?

More often in our conversations, she’d reveal her true feelings about her surroundings. In spite of my eventual, reluctant approval of the memory-care unit for my mother as her needs for help increased, she was never able to accept being there. Over a period of time I kept a record of many of her spontaneous statements because they were so painfully poignant and so full of emotional significance.

The following comments I recorded in shorthand, verbatim from Mother during a long phone call when she was more talkative and ruminative than usual. The time was about nine thirty at night, September 2, 2009, a year and a day after she entered the memory-care unit. I’ve grouped her comments into the four major themes that concerned her most.

### **ESCAPE**

“Everything isn’t roses all the time, so then I just told them that

I was going to leave.”

“I’m still here, and I think I’m just going to go back to my old life. I don’t want to be at this place.”

“I’ll feel better once I get going on my own pattern. Right now I’m just stuck. Once I get myself free, I’ll feel much better. I’ll redeem myself again. I’ll feel more alive again.”

### **IDENTITY CONFUSION**

“It’s something you thought, ‘It’s what should be,’ but it’s just different. So I made up my mind it’s not the way I want to live. It’s not me. You begin to feel like you’re nobody. You can’t live your life like this, so I just made up my mind to be in my own place.”

“It’s not anybody’s fault. I just lost my sense of right and wrong. I think I took a wrong turn when I came here. I’m just fed up.”

“You can’t be true to yourself and everybody else. It throws your being right to the core.”

“I was happy for a while, but now I’m going to straighten out my whole life like I think it should be. You know, how you felt when you were able to do things, and now you don’t feel that way.”

“I liked this place, but then I realized it’s not my life. I tried it, but it’s not what I thought it would be. It’s not my life. I did try it, but it’s just not me.”

### **FEAR**

“I’m going downhill kind of fast, and I didn’t realize it right away. But suddenly I realized my life was wasted.”

“Bit by bit [they] take your life away, wipe you out. [You] go downhill so fast. Down a little at a time, and then I’ll be gone.”

### **HOPE**

“Nobody can tie you down. I made up my mind to do something. I didn’t feel like this was what I was supposed to be.”

“I’ll maybe feel like I’m living again.”

“Don’t worry about me. This is something I have to figure out for myself.”

“Wherever I am, I’ll get it all straightened out.”

During that entire year, in various phone conversations, Mother often repeated the major themes of escape, identity, and hope, as in these two examples:

“I hope to get home soon. Sometimes I get tangled up in the atmosphere.”

“I feel neglected. The more I think about things, the worse I get. I don’t feel completely whole. I have to find something or do something just to satisfy myself. It’s not as easy as it sounds. The more you start thinking of different things, the worse it gets. You don’t satisfy yourself any way. I don’t feel like I’m the same person that I was. I’ve lost it. And now I’m going to actually find it.”

By the end of Mom's second complete year in the memory-care unit, the effects of her isolation and lack of stimulation were expressed more in fear and confusion than in hope of escape. Again, in verbatim quotations from her in phone conversations, this is how her downward spiral looked from inside her mind:

**September 30, 2010**

"I'm stuck in this house. I have no friends. Don't have anything. I feel so put out. I don't see people I know. It's just a booby trap they [people who put her there] pulled on me."

"I'm wondering where I'm supposed to be. I don't know these people. They're all strange to me. Heck of a way of living. I don't even know what this place is called."

"I've been gone from my place for a while. I feel lost. When I get back to my home, I hope I'll get to see you."

**December 28, 2010**

"It's a little scary. I feel like, 'What's wrong with me?' It feels like you're out of it. It feels like you can't control it."

**January and February 2011**

"I don't feel good [emotionally]. How much stuff they've taken of mine that I never see again."

"I feel left out of things. I'm left out of everything I had."

"It has to be true. It's been more than one day."

"My hands are tied, too."

"I'm not a necessary person now at all; I feel very unnecessary."

"I don't know how to explain it. They took care of what they thought I needed and that was it. And then they made me sit down and do nothing."