The Long Road Called Goodbye

Tracing the Course of Alzheimer's
THE LONG ROAD CALLED GOODBYE

TRACING THE COURSE OF ALZHEIMER'S

by

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Contents

Acknowledgments ................................................................. viii
Introduction ...................................................................... 1
The Early Confusional Stage ................................................. 4
   Chapter 1: Family ......................................................... 5
   Chapter 2: Catching a Cloud: 1982-85 ......................... 20
   Chapter 3: 1986 .......................................................... 25
   Chapter 4: Alzheimer’s Disease ................................... 29
The Late Confusional Stage ............................................... 37
   Chapter 5: 1987 .......................................................... 38
Early Dementia ...................................................................... 42
   Chapter 6: 1988-89 ....................................................... 43
Middle Dementia .................................................................. 51
   Chapter 7: 1990 .......................................................... 52
   Chapter 8: 1991 .......................................................... 57
Late Dementia ...................................................................... 80
   Chapter 9: Assisted Living: Early 1992 ......................... 81
   Chapter 10: Transitions: Spring and Summer 1992 ........... 86
   Chapter 11: Fall and Winter 1992 ................................. 97
The Long Goodbye ............................................................. 107
   Chapter 12: 1993 .......................................................... 108
   Chapter 13: Meanwhile ............................................... 126
   Chapter 14: 1994 .......................................................... 136
   Chapter 15: 1995 .......................................................... 174
   Chapter 16: Turning Points .......................................... 194
   Chapter 17: Going On ................................................... 220
Epilogue .............................................................................. 225
Appendix A ......................................................................... 227
Appendix B ......................................................................... 237
References ......................................................................... 245
Acknowledgments

We were driving on a two-lane stretch of I-90, my young husband and I, in the hilly rangeland between Vantage and Ellensburg, Washington. Both of us had worked all week, and it was nearly midnight on a Friday night. We were going to visit friends and family in Seattle. There was a blizzard raging on this dark night; the going was slow. As we came around a bend in the road, there was a deserted car on the shoulder. Just as we passed it, I said, “Ralph, I think I saw movement in that car!” Without a word, Ralph pulled our car off the road and proceeded very carefully to back up onto the shoulder, around another corner, until we got near the other car. It was a treacherous move. Suddenly there was a man, nearly hysterical, telling us that he, his wife, and their infant had been freezing for hours with not so much as a taillight working in their car. They had given up hope that anyone would stop. Of course they bundled in with us. I stayed with the woman and child when we got to Ellensburg, until Ralph made sure a tow had been sent and that the man had what he needed for his family for the night.

The road that is Alzheimer’s Disease is likewise a treacherous road. There is danger to financial well-being, to relationships, and to care-giver health. Surviving the care of my mother—without guilt, without bitterness, without the ruination of my own health—was no small feat. It could not have been done without help from others. Consistent help, determined help, conscious help, freely given. I came to depend upon this; I had no other choice. My husband of over thirty years now, Ralph never varied in his willingness to assist me or my parents. Though he would say it is nothing more than just the right way to live, his countless acts of kindness and his unselfish spirit were an inspiration to me.

The act of juggling children at home, a full-time career, responsibility for the care of Mother, management of a home, and attention to my
ACKNOWLEDGMENTS

husband was an enormous task. While I had a housekeeper a few hours a week, my children, The Incredible Akin Sisters, could be counted on to fill in, help out, and do additional chores. I could count on Heather (now Heather McConley) to comfort me and Janelle to humor me. They both took turns at endless errands. Most of all, they helped by being good people. They saved me the worry that many parents have.

In addition, my family listened when I needed to talk. Sometimes when I was upset or trying to work through a thorny ethical issue, this must have seemed tedious and morose. They would listen to me talk it through, and then they would have to listen again as I called long-distance to talk it over with other friends or relatives. They never told me that they were sick of hearing about Mother, although there were times when they surely were. Ralph, especially, was an amazing sounding board. I could trust his clear thinking, his strong integrity.

Finally, my family had to share me. There were times I could not visit my daughter, Heather, at school at Willamette University because I was sick, exhausted, or overwhelmed. Janelle, my youngest, gave up time with me that can never be recovered.

I am deeply grateful for the generosity of spirit and the helping hands that were part of my daily life with Ralph, Janelle, and Heather. Only a fraction of their support and astonishing honesty is chronicled here.

One of the things that is sometimes needed is for people to just get out of the way. Despite every good intention, there are times when people can’t or won’t help. At these times, it is most helpful if they just step aside. Alzheimer’s is not a disease that everyone can handle being around. Janelle had a hard time being around Mother, for example. Ralph did, too, at the end especially. I feel fortunate that some of my relatives had the grace at these times to just let me take care of things.

Many colleagues and friends told me of families who were counterproductive during tough times. Not only did they not help, they hurt. They complained, felt that they could be doing so much better, and let everyone know it. I never experienced this. My extended family was positive and constructive. My brothers, John and Tom Leonard, gave me carte-blanche in taking care of Mother. They spoke highly and gratefully of me. They gave me solid support, start to finish. John took care of all of my mother’s finances after our father passed away. Tom attended to the estate sale, the
cleaning, and re-carpeting of their home. His family also provided great vacation times for Ralph and me.

Because this book is a case study wrapped in a story, the purpose of this book is to educate, not just to entertain or remember. Given this purpose, the necessity for honesty—sometimes in intensely personal areas—is greater. My whole family—husband, children, brothers, and sister, Mary Lou Stowell—had to be willing to expose some of themselves. As I agonished over who and what to reveal, how much to expose, I was sustained by one thought. My mother herself would have censored none of it. She would have laid herself bare to make a contribution to the knowledge of this disease. I and all who read and learn from this book are indebted to those who shared themselves in this way. Some of the names of the residents of caregiving facilities and their relatives have been changed to protect their privacy.

My two aunts, Aunt Babe (Gudrun Layton) and Auntie Ethel (Ethel Van Dyke) were also sources of comfort and help. I struggled with whether or not I should quit my job and take Mother into my home. My Auntie Ethel could tell me what she knew Mom had wanted. When Heather got married, I agonized over whether to bring Mother to the wedding. Aunt Babe could advise me on how Mother would prefer to be treated. Both aunts helped me think through the ethical issues that arose.

Unfailing help came also from a number of friends. I don’t know what I would have done without Mom and Dad’s best friends, Homer and Betty Schmitt. I sought their wise counsel often, and they were so thoughtful and gracious. Although they lived in Seattle, three hours to the north, they visited Mom often enough to give me feedback on her care and progress. So close to a situation that was intense and consuming, I sometimes needed the advice of those who loved her, but who stood back just a little from it.

I deeply appreciate the help I got from a number of professionals. Connie Easter was the administrator of the Cascade Inn, a retirement community. Professionals at the University of Washington, where my mother was part of a long-term study, included Meredith Pfanschmidt, the nurse in charge of the Alzheimer’s study, and Zilpha Haycox, Lead Psychometrist. Dr. Richard Moller, our family dentist, patiently guided us through a series of procedures and months of work to restore Mother’s mouth after years of neglect. Dr. Manuella Laderas, Mother’s internist,
broke all the molds. An exceptional listener, she went so far as to give me
her home phone number. She visited Mom in her foster care home. Dr.
Laderas went out of her way to be there for us as an excellent physician
who walked with us to the end.

Special thanks also go to my editor, Brent Spencer, first for appreciat-
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managed an adult foster care home in her own home, and Ken graciously
put up with it! Ann took such loving care of Mom; I could not have made
it through this without her. She was helped by Ana Bordea, a recent
Romanian immigrant, who knows how to love, nurture, and tend—gifts that
transcend language and culture. Janice Ripp also worked at Annabelle’s
Foster Care Home during Mother’s last year. Janice brought intelligence,
capability, and spiritual support to her work. For the loving, warm, fun, and
secure atmosphere these people provided my mother, there are no words.
When I think of them still, they give me hope.

Charlotte A. Akin
Battle Ground, WA
Introduction

When I was five years old, in 1953, my mother took me to South Dakota to visit my aunt and grandmother. I have only one memory of the trip. My Aunt Dagny took me to school with her for a day. She was a teacher in a one-room school house. She taught eight grades and stoked the wood stove. Watching her teach and being in that classroom felt to me like home. I knew forever after that I was born to teach.

Of course I became a teacher. I’ve taught preschoolers to adults. So I am always bothered when I come upon information that people truly need that is in a format they are unlikely to access, such as medical journals. I wonder, How could I teach this and make it interesting?

When my mother was diagnosed with Alzheimer’s Disease, I wanted to learn three things. First, I wanted to know the course of the disease. How long does this last? What will happen to my mother over time? These questions are important not just to satisfy curiosity. The answers affect legal and financial decisions. They give some idea of the care that will be needed in the future.

The second question was, "How does this disease impact family members?" How do people cope with seeing a loved one degenerate ever so slowly? Are there any strategies that might help with this? How do children react to the disease? How do family members respond to one another when some react to illness by withdrawing? Could my ailing father take care of a wife with Alzheimer’s? How much and what kind of help would be needed from other family members? There are many layers to the impact of Alzheimer’s upon a family.

Third, I wanted to find out what good care looked like. I wanted to know the options. Would in-home care be best? An institution? Should I move Mother in with me? What costs are involved? Does care even matter to the person with Alzheimer’s? What would matter to my mother?
These were the questions I tried to answer by reading medical books, caregiver books, memoirs, and by living with this disease. Once I found answers, there remained the question: *How could I teach the information to others and make it interesting for them?* What kind of format would people be most comfortable reading? The answer: I could do a full-term, start-to-finish case study and write it as a *story*.

Any medical disease or psycho-social disorder generally has a cluster of symptoms. Each afflicted individual manifests most, but not all, of those symptoms. So while a case study would not necessarily cover every single thing that might happen, it covers many things—and those in depth.

A case study is a way of illuminating clinical information by making it personal and giving it a setting. It looks at one person’s experience in depth over time. Through the power of story, the reader is taken on a journey that chronicles the disease. Occasionally in this story I want to highlight one aspect of Alzheimer’s by showing several examples over the course of a year. Then, as the story resumes, it goes back to an earlier date. While the time line may be briefly interrupted, this gives the reader a closer look at some critical issues.

I was tempted to begin the story at the beginning of Alzheimer’s Disease, or even later, when caregiving became an issue that impacted the family. But there was the realization that so much of what helped me to help my mother was knowing her history. Alzheimer’s robs a person first of recent memories, then gradually of more distant ones. Knowing about Mother’s early life on a farm, for example, gave me the idea of taking her into the country for drives when she was “way far back” with the disease. Her eyes yearned, then, to see fields and barns. Instead of taking her to a grocery store to buy apples, I drove her a few extra miles to a farm’s produce stand. We sang old songs. So Mother’s story is best told with a brief description of her beginnings to give the reader a sense of the woman who was—before there was Alzheimer’s Disease.

I was also tempted to write this story without much family history. After all, nobody needs to know the family’s business—the good, the bad, and the ugly. There were two important reasons to include the context of family, however. First, family is an Alzheimer’s victim’s primary human resource, as he or she increasingly has less ability to function. Second,
people coping with Alzheimer’s need hope. I did not want readers to feel that while *our* family somehow struggled through this, theirs would not be able to. No family is perfect, and Alzheimer’s does not wait for the perfect time and place to strike. So without necessarily divulging all the family secrets, I did include enough of a sketch to give a realistic picture of how one family, however flawed, made their way along the road.

The road, of course, is Alzheimer’s Disease. Its length is measured in years. Some sources break this illness into three clinical stages. The amnestic stage primarily describes early memory loss. The dementia stage is the middle stage that deals with cognitive (learning, reasoning) problems and emotional upheaval. The final vegetative stage is where the patient is unable to care for himself entirely. For instructional reasons, I chose a source which breaks this long road into five stages.

There are people on the road. The traveler is a victim of Alzheimer’s Disease. The cadre of caregivers—family, friends, and professionals—is the vehicle that supports and helps the traveler as the long journey progresses.
The Early Confusional Stage

The first stage of Alzheimer's is difficult to detect. The victim may just be a little forgetful. Recent events and conversations are most affected. These are the things that happened earlier in the day, yesterday, perhaps last week. The person may unconsciously repeat himself or herself, though usually is able to compensate and cover up a gradually worsening memory.

Driving reactions may be slightly slower. Driving to familiar locations is not a problem. Traveling to a new place is. A person may easily become lost in unfamiliar territory.

The person may have less initiative socially. He or she may be less tactful and/or spontaneous in social situations, often using denial as a coping mechanism, which causes others to underestimate the severity of symptoms. There may be widely separated events of irrational behavior. Emotionally, the person may seem slightly unhappy or anxious, but others are mystified, since the causes for these emotional changes are not clear.

The kinds of problems that appear in this first stage of Alzheimer’s Disease are subtle. They can be easily dismissed, laughed off, hidden, and denied. Alzheimer’s is not usually diagnosed at this early stage (Gruetzner, 1984).

This is a summary of the clinical definition of the first stage of Alzheimer's in Howard Gruetzner's book, Alzheimer's: A Caregiver's Guide and Sourcebook. The coming chapters will illustrate how this looked and how it played out in my mother’s life. Dates are included as mile-markers, to give a sense of time, to measure the length of the road. This format will be repeated throughout the journey.
Chapter 1

Family

Unlike other trips I’ve taken, the journey with Alzheimer’s had a shadowy beginning. It’s hard to pinpoint the date that I joined my mother on this road, hard to say when she began it. Certainly it began before I started gathering information, before I was confronted with all the problems of providing care for her. In a way, it even began before I went to visit my Aunt Dagny.

"Do you think your mother is happy?" she had asked, suddenly quite serious.

We were sitting in a cozy mobile home in Idaho Falls, Idaho. She was recovering from cancer surgery, and I had traveled here to see her. Her place was nothing special, just a neatly kept single-wide in a mobile home park where she lived with her husband, Jim. She had taught school for forty-three years and raised seven children. And she could tell a tale like nobody else. So we sat there together in the living room darkened by wood paneling, and she sat back and talked for the better part of three days. I could have listened to my Aunt Dagny for months, learning the lessons woven between the lines.

All five of the Anderson children had been born in a one-room sod house on the prairie of South Dakota, the children of homesteaders, immigrants from Norway. Their mother, short and plump, actually gave birth to six children. One of them, Agnes, had died of appendicitis at the age of four, so my mother, who came later, was also named Agnes in order to honor her paternal grandmother. Their tall and dark-haired father, John Anderson, was a stern and serious man. He helped build the Lutheran church near the tiny town of Lemmon, cared for his neighbors, and was
involved in local politics. After befriending a man who died leaving no family, the struggling immigrants inherited a home. They gratefully moved into larger quarters. By then "Little Agnes" was five.

Life was simple. Little Agnes had few playmates and fewer toys—a prized shoe box and a doll, Pethernella, which she shared with her cousin, Magnhild, who lived on a neighboring farm. Out on the stark and endless prairie, she played "funeral" with her two brothers and sisters, Dagny and Gudrun—called "Babe" for the obvious reason. Her older brother, Einar, tall and brooding like his father, was always the minister. Little Agnes played a mourner, because she could cry. The actors changed roles from time to time. Often Babe was the deceased, and Dagny and another brother, Arne, might be the mourning parents. Without television or many books, this was the kind of drama familiar to the isolated farm children growing up.

With children from neighboring farms, they learned to smoke and kiss behind the barn. They learned to drive a Model A on a frozen river bed, making Little Agnes a nervous driver for life. Their father played the fiddle. Neighbors sometimes gathered for a dance, to sing, or tell stories. It was no surprise, then, that Dagny became a marvelous story teller, Babe was known for her beautiful singing voice, and Little Agnes never lost her love for a dance.

When their brothers finished eighth grade, they went to work on the farm, and there they spent the rest of their lives. When Dagny finished eighth grade she went on to high school. Their mother was mystified at why a girl would want an education, but Agnes followed suit, moving to a nearby town and living with a family as their maid until she could graduate. A neighbor loaned Dagny money for college. When she finished, she gave Agnes money for college. When Agnes finished, she gave money to Babe. Babe paid back the neighbor. All three became teachers in one-room schoolhouses in South Dakota. All three later moved beyond the borders of their home state.

Agnes worked as a teacher for six years, and Babe also taught off and on for several years, living all over the world with a husband in the military. Dagny alone made teaching her lifelong profession.

Dagny talked and fixed lunch for us. She wouldn’t let me cook; even in poor health, she was the boss of her own kitchen. She and Jim would
have a little nap after lunch, while I would go for a walk. Afterwards, she would tell me the stories of the children she taught, throwing back her head for a good laugh from time to time. One had told her she was beautiful. Dagny never put much stock in her looks; this expression of love from a child amused her.

As the days and stories began to wind down, Aunt Dagny asked me, "Do you think your mother is happy?" At the time I knew some of where the question was coming from. My parents lived in a large and beautiful brick home overlooking Puget Sound in the suburbs south of Seattle. Cool breezes scented with the salt water wafted through open windows in summers. In winter, fog and drizzle from the water blanketed the neighborhood, and tall evergreens tempered the wind. Even then there was a softness in the atmosphere that surrounded them when compared to the harsh winters and hot summers of Idaho. My parents, while not truly wealthy, were very comfortable in their retirement. They traveled widely and had many friends. Mother was habitually cheerful and also enjoyed perfect health. She was into health and exercise long before it was popular. In the morning at her house, if she wasn't on a brisk walk to the beach, she was exercising with music on the radio or TV. Yet here was her ailing sister asking me if I thought she was happy.

What I didn't know at this time was that my Aunt Babe had been openly insulted by my mother a couple of times in the past few years. Babe had told Dagny about it. I also didn't know about an incident that happened at a family reunion in 1982. It included friends from South Dakota as well as relatives. The first day of the reunion was hosted in a spacious home overlooking Lake Coeur d'Alene in Northern Idaho. It was a lovely summer day, so people gathered on the deck outside as well as in the living areas of the house. Both Aunt Dagny and Aunt Babe were there with their husbands. My cousin Pee Wee was there with her twin sister, Fatty. Of course these are not their real names. Daughters of Aunt Dagny, one twin was thin, the other plump at birth. My mother had nicknamed them then and there, and the nicknames stuck. Their names are Marlene and Maxine. Maxine, who is Pee Wee to me, is quite tall. Marlene, who will always be Fatty to me, is not at all fat. But both of them are lots of fun at a party,
regardless of what they’re called. At the reunion Mother saw Fatty and gave her a big hug. She looked right at Pee Wee without the slightest hint of recognition in her eyes. Pee Wee was quite hurt. It took over two hours before Mother looked at Pee Wee as though she had just come, recognized her, and gave her a big hug.

This incident was important from a couple of perspectives. First, it was not just a moment of forgetfulness, common to all of us. It lasted quite some time, and it occurred with someone Mother knew well and loved. Pee Wee had once lived with our family. Furthermore, when Pee Wee later tried to tell her own mother that Mom didn’t recognize her, Aunt Dagny got mad at Pee Wee for saying such a thing! Pee Wee was hurt again. We came to understand much later that this was actually a common reaction of people when told about Mother having Alzheimer’s. It was at first hard for people to believe. There is a stigma and a horror to losing one’s mind. Friends and family alike would react in a kind of angry denial, mad at the messenger.

But now, a few years later, Dagny herself was sensing that something was wrong with her sister. Although she was battling cancer in her humble home, it was clear that Dagny was at peace. She was happy. Was her sister? And why was I, all of a sudden, being asked to evaluate my mother? Lately my dad had been asking a different question: “How do you think your mother looks? Do you think she has lost weight?” He’d asked that of me several times in the past few months. Each time I’d told him that I thought she looked great. No, she didn’t look thin.

Well, compared to Dad, of course she was thin. An epic figure, he was larger than life in many ways. Always playful and the life of any party, he was a huge man, over six feet tall and weighing more than 300 pounds. Mom was forever trying to get him to lose weight. She was an avid reader and a particular interest was nutrition. It dovetailed nicely with her bent for exercise. So she read, dieted, exercised, and preached a bit, too. And Dad dutifully, gratefully ate whatever his fit wife fixed for him before leaving for the office each day. What he didn’t say was that "the office" he was referring to was a nearby Winchell’s Doughnut shop. He never seemed to mind Mother’s preaching and special diets for him, as long as they didn’t seriously interfere with his eating.
Dad had met my mother through his best friend, Homer. Dad and Homer grew up in Kansas during the Depression. Charles "Bud" Leonard was as tall as Homer was short, as rough around the edges as Homer was smooth. Bud’s father had been the town drunk and had run off with a woman, leaving Bud and his brother, sisters, and mother to fend for themselves. Still, Bud was eternally optimistic, athletic, bright, and more entertaining company than anyone else around. Bud’s oldest sister, Lilian, moved to Seattle and married. Bud visited her once, and when he returned to Kansas, he went straight to Homer, pulled him off a tractor, and told him the streets of Seattle were paved in gold. Homer left Kansas and moved to Seattle with Bud.

Soon Homer had a girlfriend named Betty. She was living with her sister and another young woman named Agnes, whom they had met at a bookkeeping school in Wenatchee, a small Central Washington town. Agnes had been a teacher but decided to move West and do office work. Together the three young women went to Seattle to find work. It was only a matter of time before Homer and Betty introduced their roommates to one another. Agnes was not impressed with Bud, the young man who slapped her on the knee during a funny part in the movie. But somehow his rough, boyish charm eventually captivated her, because in 1942 she married him.

Bud and Agnes had their first child just before Bud went to France in World War II. Agnes took her baby, Mary Lou, to South Dakota for a time and lived with her parents. Then she went back to Seattle and settled in with Bud’s sister, Lilian, who was also raising a young daughter while her husband was overseas. After the War, Bud settled his growing family in Seattle. Four children grew up in our family. After Mary Lou, I was born second. Then came John, named for his maternal grandfather, and finally Tom.

Mom and Dad established their young family in a middle-class neighborhood on Beacon Hill. Dad became a buyer for Sears. Mom stayed at home raising children in a close-knit neighborhood of like-minded families. We spent Thanksgiving with Homer and Betty’s family and other holidays with Auntie Lil (Dad’s sister Lilian) and her family.

Dad bought a small dairy farm in Ellensburg in the Yakima River Valley, a two-hour drive from Seattle over to the east side of the Cascade
Mountains. Managers lived full-time in the big farmhouse, while our family had a one-room cabin with a wood stove. Mother packed us up for trips to the farm nearly every weekend. Friday nights or early Saturday mornings found the six of us bundled together in the car singing songs with the radio, playing car games, putting on chains mid-trip in the winter, fighting, laughing, and sleeping along the way.

On the farm we had a different life than the one near the center of Seattle. Dad shed business suits and ties for his blue striped bib overalls. Entrepreneurial in spirit, he was the consummate sidewalk supervisor in a boyish, Tom Sawyer sort of way. Working for Bud was a privilege. When the hay needed to be cut on the farm, Dad could get his city slicker buddies from Sears to don overalls and spend weekends cutting hay. Homer, by now also a Seattle businessman, was good natured enough to keep his farming skills sharp in this way, too.

Mother cooked on the wood stove in the country and enjoyed all the modern conveniences in her home in the city. And while we lived in a close, multi-ethnic neighborhood on Beacon Hill, there was no end to the fun we had just as a family on the farm. We learned to ride a horse. Yes, one horse. We took turns. Because Tom and John were younger and small, they learned to ride calves, too. A big rope hung from the ceiling of the old red barn. We stood in the loft and swung from it. Mary Lou and I converted an old chicken coop into a playhouse and outfitted it with apple crate cupboards and old dishes from the Goodwill store. John and Tom could target practice with a BB gun. We all learned to swim in a large irrigation ditch that ran through the property. Eternally modest, I even went skinny-dipping once in the night with Mary Lou and one of her friends when we’d slept outside under the stars. Among my favorite memories is Mother sliding down a snow-covered hill on a bedpan she’d found at Goodwill.

Resourceful to a fault, Mom used the farm as her classroom. If a cow was about to give birth, for example, she would herd her children to the loft of the barn. We would lie down flat on our stomachs and peep over the edge to the cow below. We would have to be ever so quiet while we watched; we were not allowed to disturb the cow. The family grew close taking those trips over the mountains to the farm. Between that and Beacon Hill, it was the best of both worlds.
In addition to these warm memories, there was a shadow over our family. Its name was alcoholism. Like his father, Dad had a drinking problem that wrought havoc in our lives. Sweet as life was on Beacon Hill and the farm, there were times of horror, too: waking up in the morning to see my father sleeping drunk in the street outside our home, having Dad come to our Christmas programs at church falling-down drunk, seeing my mother’s tears as she worked at the kitchen window. These were just a few of the potent signals that all was not well in the Leonard home.

In 1960 Dad sold the farm. We also moved to a suburban community on a Puget Sound beach that year. It was the beginning of a very bleak time in the history of our family. Here the neighbors were strangers who hadn’t known us all our lives. The following year Dad’s sister, Lilian, died of cancer after suffering for many years. Soon after the move, Dad had back surgery and then left Sears for a variety of jobs. He was a manufacturer’s rep and insurance manager. Then he bought a "cafe" in a run-down industrial part of Seattle. Small and dingy, it was the kind of place that served sandwiches at lunch time and a lot of beer. The teenage girls who waited tables were his daughters. A year or two later Dad sold the place and started a wholesale toy business. Mother kept the books, and John and I both worked in the warehouse as stockmen, filling orders, unloading trucks, and moving merchandise. Nevertheless, the business failed, bankrupting the family in 1967, my second year of college. By that time Dad’s drinking was so severe that Mother filed for divorce, and they were separated.

But Dad also had an invincible quality. After his back surgery, the doctors told him he’d never walk again. Coached and coaxed by his children, he was walking within a few months. He went bankrupt in mid-life. The bank gave him six months to raise enough money to save our house. We lost everything, but Dad saved the house and found an occupation for himself in real estate that was better for him in every way. When his wife started divorce proceedings against him after twenty-some years of alcoholism, he quit drinking and won her back. People appreciated Dad for his mind and his many social skills. But those who were really close to him respected him most because he just never gave up. He could seem to be down for the count and somehow come up again swinging.
Dad was forever fun and funny. He was mathematically brilliant. When his mathematical mind wasn’t being exercised in business, or counting cows, or figuring milk production, it was being expressed at playing cards. Saturday nights he often spent with his friends playing poker or bridge, depending on the group. Totally unpretentious, rough around the edges, he knew a zillion people, and everybody, high or low, truly loved him. Often when someone called him on the phone and said, "How are you?" he responded with, "Well, I'm lovable." And so he was.

Certainly he was adored by his wife who was his companion in business and life. After the farm was sold, Mom went camping and fishing. She went to New York City, Alaska, and anywhere else Dad seemed to need to go. She also took trips to South Dakota with anyone who would go with her. She went to Norway with a childhood friend. While she loved her home, "Little Agnes" was known as a good sport who was ready and willing to go just about anywhere.

Mother also took her children to church. On Beacon Hill we went to the Congregational Church. After the move to the suburbs, we went to St. Paul’s of Shorewood Lutheran Church. Disenchanted with the organized church from childhood, Dad rarely went. But Mother had her children in Sunday School as soon as they could walk, and she was not opposed to taking a carload of neighborhood children along as well.

Undoubtedly rooted in her faith was a basic integrity that, in spite of our differences, I always respected. The wisdom of Alcoholics Anonymous states that girls raised in alcoholic families either marry one or become one. Mary Lou and I never did either. Mother never let us believe that excessive drinking was acceptable. Somehow she balanced that with an enduring love for Dad which we never—not even during divorce proceedings and separation—doubted.

Mom loved to learn, and so she took classes. She took sewing classes, short hand classes, bookkeeping classes, downhill ski lessons (when she was sixty), real estate classes, cooking classes, yoga classes, aerobics, and Bible study classes.

She was also a reader—not a particular reader—just a reader. She knew from her unending reading a little about a lot of things. An expert at home remedies, I'm sure this interest began when she was a girl back in South
developed an interest in medical research and nutrition and was aware of alternative medicines decades before any of these became popular.

Mother’s perfect health was documented by a medical history consisting of some fillings and bridgework done on her teeth. She’d also had a little bladder repair done vaginally when she was in her fifties, needed because of seven pregnancies. (She’d had two miscarriages and a stillbirth in addition to her four children.) The doctor took out her uterus at the same time, for convenience. The surgery was done on a Tuesday. I arrived at 10:00 P.M. Friday to help, having traveled 300 miles after work from my home in Spokane. Mom was up vacuuming when I got there. In her late fifties or early sixties, she lost her sense of smell. We never knew why. She had an eternally sunny disposition and always said that if she had to lose one of her senses, smell was perhaps the easiest one to lose. And that was it, until she was nearly 70 years old. She very rarely even got colds or the flu.

In our family we all had nicknames. Tom was called Pooh for a while after Mother read Winnie the Pooh to the family out loud. John, who had a more serious nature, was Eeyore. But we made up Mom’s nickname ourselves. She was The Doctor Agnes, K.E. (Knows Everything). Given all her classes, remedies, and reading habits, it was no wonder.

As Dad was now in a financially comfortable retirement, his battle with alcohol behind him, the question was: Was this wife of his happy? His answer to my Aunt Dagny would have been, "Hell, yes. Except for that business with Mary Lou . . ." 

Authorities on children of alcoholics say that predictable patterns and roles develop in these families. Mary Lou’s unfortunate role was that of the "child" who acts out problems and rebels, becoming the scapegoat for the real problems facing the family. Dad never got any help for his alcoholism. He just quit drinking. He never understood either the problem or the related family dynamics, though he had lived with them all his life. As a consequence, he never understood Mary Lou.

Mary Lou was born when Dad was on his way to France in World War II. Mother took a train to meet him in Chicago soon after Mary Lou was born, so he could see her. He didn’t return until after she was over a year old. Somehow Mom got it into her head that Dad and Mary Lou could not
have a good relationship because he was gone during her infancy. This is something I heard from Mom for as long as I can remember. She said it to Mary Lou and Dad as well. In truth, it was the relationship between Mom and Mary Lou that was abysmal. By the time Mary Lou was a teenager, she was both beautiful and stormy. She left home at sixteen to be with her boyfriend, who had joined the Marines. When they returned, they married. It was within weeks of her seventeenth birthday. She and Arne—still married—raised two sons, living most of their married life in the suburbs south of Seattle. While they were geographically close to Mom and Dad, the relationship was distant.

As I sat sheltered in the somewhat overheated living room of my elderly Aunt Dagny, I reflected on my own painful relationship with Mary Lou in the past year. We had been close after we became adults. But the recent strain in her relationship with Mother was putting a strain on our relationship as well. Mary Lou would call me up and swear that Mother was stark raving mad. I lived 300 miles away. I couldn’t tell. Mary Lou and Mother had never gotten along. Mary Lou told me, for example, that Mom kept calling her up and asking her to go to an aerobics class with her. Mary Lou was—and is—far from the aerobics-class type. She would tell Mother that she wasn’t interested and why. Then Mother, paying no attention to Mary Lou’s wants and needs, would ask again. To Mary Lou, it felt as if she were being pressured. Looking back, I can see that these episodes may have been early memory lapses. By the end of 1985, Mary Lou’s relationship with her parents was irreparably strained. It had always been fragile, and during this time, it simply was breaking into pieces. As a defense, Mom and Dad decided that Mary Lou was the one who was crazy. Upset and depressed about this, Mother couldn’t unravel it, couldn’t straighten it out. She grieved over it.

Dad would have said that Mary Lou was the source of any unhappiness Mother felt. But Mary Lou, once again, was only a symptom of a much larger underlying problem. And by this time, she was so hurt and angry that if anyone had dared ask her if her mother was happy, she would have responded that she couldn’t have cared less.

In a mirror opposite of Mary Lou’s relationship with our parents, our
brothers, Tom and John, lived farthest from Mom and Dad and enjoyed the closest relationships with them. John, although born third in the family, was the first-born son. John was just two years younger than I. As a young boy, John was fascinated by Native Americans and their cultures. He loved to hunt and fish, loved the out-of-doors. He often said that someday he'd live with the Indians and live off the land. John came of age in the heart of the Viet Nam War. Dad had some connections that got John into the Coast Guard after high school, whereupon he was sent to the North Pole on an ice cutter. This experience made a reader of John. I think it may have turned him into a writer as well, if he had made one more trip up there. His letters to me while I was in college were deep and philosophical—and full of his hatred of the Coast Guard and ice! When John finished his tour of duty, he went on to school, graduating with a degree in finance.

John married Denise while he was still in college. After graduation they lived in Seattle and then moved to Northern Idaho, just across the Washington border. Denise was part Cherokee. She and John settled into a cabin on Hayden Lake and John got involved in real estate and timber lands. It made me laugh to see the way that he was realizing his childhood dream.

John and Denise were close to Mom and Dad. John is like Mother's side of the family in disposition. I think he reminded her of her father and oldest brother. All had a sensitive, serious side and their humor was dry—not goofy like the man she had married. John and Dad often hunted and fished together. Mother and Denise would go out and pick fruit or shop on these trips. Though John and Denise did not have children until they had been married about ten years, their children were closest, also, to our parents. They visited Seattle often, staying with Mom and Dad.

While not a man of many words, John's words are always well-chosen. Like Dad, he has never been one to delve into the psychology of things. Had Aunt Dagny asked John if his mother was happy, he would have said, "Yes." He brought out the best in her, and that is the face of her that he saw.

My youngest brother, Tom, lived with Mom and Dad until he was nearly thirty. He was addicted to cocaine and alcohol, something Mary Lou, John, and I all individually spoke to our parents about. We all gave
the same message. Allowing Tom to live at home well into his twenties was enabling his addictions. The message fell on deaf ears. Tom sank ever deeper into the abyss. I was closest to Tom when we were very young. He had asthma from the time he was born and later a bone disease that kept him bedridden for a year. Still, he had the sweetest disposition and a kind humor. Like Dad, he could use humor to brighten any day. He could manipulate a smile from a frown with a single word. During all the drinking years, it was Tom who could coax Mom into laughter. She was very close to him and not able to let go. It broke my heart to see him forever at home, losing ground at a time when he needed to be growing into manhood.

When Tom was around thirty, he moved to Alaska. He’d been up there a time or two before, always returning to Seattle. This time he stayed long enough to run into the kind of trouble that put him before a judge who offered two options. He could get sober and get help, or he could go to jail. Somehow he had just enough gray matter left in his fried brain to choose the first.

As I sat with Aunt Dagny facing her question, I knew that Tom’s answer, even after months of work in recovery, would have been, "Happiness? What’s that?"

When I heard about Tom getting help from my comfortable home in suburban Spokane, where my two little girls attended a private school and took piano lessons, I sat down and wept for joy. The Good Lord had reached down into the abyss and rescued my little brother.

Speaking of God’s hand from Heaven, I’d had a special friend in an older woman named Ruthie who lived across the street from us on Beacon Hill. Ruthie had heart disease, and I actually lived with her half the time for over two years when her husband, a railroad engineer, traveled. I tended Ruthie, as she tended me. I cooked and cleaned for her. I even had my own bedroom at her house. She called me "Hollywood" and thought I was hot stuff. Ruthie remained my closest confidante until she died a few years after our move to the suburbs. She had only met my new boyfriend, Ralph, once—and she told me to hang on to him.

This was during the time when everything was falling apart at home. I remember many dates with Ralph where I would just sit and cry because
my home life was such a mess. He had no way of understanding. He was just a good listener. I must have been a barrel of fun as a date.

After high school I moved across town to the University of Washington, where I lived on campus. In contrast to high school when my family had been a huge and unhappy part of my life, at college it hardly existed. Dad drove me to the dorm where he dropped me off at the curb with my belongings. That was the closest anyone in my family ever came to visiting me in three years. I went home for holidays, and there were occasional phone calls to Mom. I talked often with Mary Lou and went out to visit her and her family whenever I could get a ride there. I got a few letters from John when he was in the Coast Guard.

After Ralph and I married, we lived three miles from my parents in the home Ralph was raised in. They never saw the inside of this home either, though I did invite them. A year later, Ralph and I moved across the state to Spokane.

Mother always felt I was too sensitive, too caring. Until I was a teacher, I believed her. Then I realized that being sensitive was an asset. I came to believe that it wasn’t possible to be "too sensitive" or to care too deeply, any more that it was possible to be too pretty or too capable.

After teaching a few years, I "retired" to start a family. One wintry day, after driving six hours, we arrived at Mom and Dad’s with a cranky baby, which made me anxious with worry for my little Heather. Then Mother started in with the over-sensitivity speech. But she did not get far this time. I stopped her cold by saying, "And if you can’t be sensitive and care for your own child, Mother, who in this world do you care for?" It was a double-edged question; I felt uncared for by her. She never bothered me about my "over-sensitivity" again. It was ironic that her life would depend one day upon my capacity to sense her needs and to care for her.

Our Janelle was born shortly after a transfer back to the Seattle area. I was ill after Janelle was born, suffering from fifteen different infections in six months. From Dad, there was nothing, no real communication of any kind. He distanced himself, I guess. From The Doctor Agnes, K.E., there were occasional questions wondering if I needed help. When I said I did, she let me know how she hated to drive on the freeway. Or in the rain. This was hard to take from a woman who had gone to South Dakota two days
after Janelle was born and had gotten herself to Norway a couple of years earlier. It fit into a larger, long-term pattern. When I got well, it was a time of deep disillusionment and grief for me. I nearly left my young family, wondering if families weren't an exercise in futility.

It was time to squarely face this problem. I bitterly confronted Mom and Dad with the fact that I understood now that I could fall off the face of the earth, and they wouldn't much care, certainly not enough to drive across town. If they really wanted any kind of a relationship with me, however, they would at least have to pretend occasionally to care, because I also now knew that I had absolutely nothing to lose. Mother cried in response to this and was genuinely sorry. Dad said he was too old to change; the relationship was over. I'm sure he expected me to "come around" but I honestly and deeply meant what I had said. It took him some time, but eventually it was he who "came around."

That time was my Valley of the Shadow of Death. It is only the hand of God that can bring one through the Valley, and that was my experience. When it was over, I knew three things. I knew I loved and wanted my family of Ralph, Heather, and Janelle more than life itself. No one could love them more than I could love them. Second, I knew that to be whole, I had to love and forgive my parents. No matter how I was treated, to stop loving them would be giving in to something very wrong. This conscious decision came at a greater cost than I ever imagined at the time. Finally, I had to leave my past in the past and not allow it to poison my future; I had to go forward and leave the rubble and the Valley behind me.

This was a pivotal time in my life. There were things I didn't know, didn't understand about it until later. I have come to understand that it is harder to lose people in life than it is in death. For example, to have a husband walk out after twenty years of marriage would be harder to bear than his death after the same period of time. There is not only the loss of him to bear, but also the rejection. Similarly, I grieved the loss of my parents at a time when they were still living. It was a thorough grieving. When I was done, it was over, and never would I grieve the loss of them like that again.

But I have also come to believe that I would never have been emotionally healthy without going through the Valley and coming—by conscious
choice—out of it. My whole concept and definition of love was revolutionized in this process. We often think of love as an emotion. The love I committed to was active, not emotional. Having been on the receiving end of inactive "love," I had decided that love without action did not exist. It was empty love—a contradiction in terms. So when I committed to loving, it was a commitment to action, not to a warm, fuzzy feeling. I committed to staying in relationship, to civility, to helping when needed, to being included in family events.

Another thing I did not understand was that in finishing the grieving process, it left a part of me emotionally detached. This odd combination of committing to love and being emotionally detached (at least temporarily) actually turned out to be an asset when in later years my parents needed help.

Certainly I did not know that I’d spend years on a road called Alzheimer’s Disease, and that it would change me even more.

By the time Janelle was a year and a half old, Ralph was facing some disillusionment of his own. He quit his job, sold our home, and moved the four of us back to Spokane. We settled back into the familiar suburbs we’d lived in before.

Now our girls were in elementary school and were having a high old time with their father as I was on this short trip to visit my Aunt Dagny.

In that close living room she leaned forward a little to study my response. "Do you think your mother is happy?" she asked me.

Without a moment’s hesitation, I said, "No."
Chapter 2
Catching a Cloud
1982-85

The Doctor, as we often called Mother for short, was born in 1916, so in the early 1980s she was in her late sixties; Dad was a few years younger. They were mostly retired. Dad still dabbled in real estate; The Doctor continued to do some bookkeeping for a friend.

Their brick home in Shorewood on the south rim of Seattle overlooking Puget Sound had an airy quality to it. Large picture windows graced the whole front of the house for a panoramic view. From here they could watch ships pass, follow ferries on their routine voyages, and see the fog lift in the morning. Vashon Island was in the distance. The patio in the back of the house was bordered by a little wood and enjoyed cool breezes of the salty air that flowed off the water. Inside the house the walls were the warmth of wood or an off-white that just hinted at the pastels The Doctor loved. This was the home they had moved into with their four children after leaving Beacon Hill.

In contrast to their home and its peaceful qualities, their lives were in constant motion. They always enjoyed a busy social life, and this intensified now that they were no longer burdened with child-rearing and work. Hard times were behind them. This was a time to enjoy.

Even though Mom and Dad had strained relationships with both daughters, this has to be viewed as a flaw, not as a characteristic. Mother was characteristically warm, loving, and helpful to people. Before the age of therapists, she was often sought out by her friends and neighbors for her wise counsel. Dad never knew a stranger.

Good to a fault with their friends, their door was always open. Friends
and relatives from far and wide were constantly dropping in for a day or two or a week. Mom and Dad never locked the house unless they were leaving for a week or more. Everyone knew that the key was in an old "snoose" can in the brick planter by the front steps if they happened by and the door was locked.

My folks were always on good terms with neighbors who also frequented their home. It was an unusual day when at least three neighbors didn’t drop by for a cup of coffee and some chit-chat. One neighbor usually visited in the mornings. Early evenings another neighbor came down the hill, or one of his kids, or one of his kids’ kids. The next-door neighbors were in and out all day long. Frequently, Dad would be "allowing" someone to fix his plumbing or re-wire something for him. Perhaps he needed help in the yard or with patching the roof? The motor home might need some adjustment. People loved to help Dad, never noticing that he mostly provided the conversation.

Then there were the bridge clubs. They belonged to a couples’ group that got together on Saturday nights. The Doctor also belonged to a women’s bridge club. Both of these went back nearly thirty years. Mother belonged to the Lutheran church and sang in the choir from time to time. Dad played poker with buddies in White Center.

And there was the telephone. Dad talked to Homer daily. He also kept in close touch with many other friends and relatives, near and far. People called him about real estate. Should they buy this? Would he sell that? Dad loaned money to just about everyone he knew, so there were calls about one financial transaction after another. The phone was going constantly.

Had this been their only social life, however, I’m sure they would have fainted dead away from the boredom. There was, after all, a whole world out there with things to see and do. So they saw and did. They went fishing and dug clams. They camped. They went to Vegas and stayed in hotels. They took the ferry to the San Juan Islands and played bridge; they harvested oysters which the Doctor would crack and eat raw on the beach. They went boating and set out crab pots. They had a place at the ocean, another in the mountains—pieces of land where they could park a trailer or motor home or pitch a tent. They went to reunions in Kansas, checked out Mexico, Hawaii, Canada, and looked up relatives on the East Coast when
they were in the neighborhood. Mother said that it didn’t matter where they were, there was always someone who knew Dad. They could be in a little drugstore in some far-flung place halfway across the country and someone would call out, "Well, Chuck! How the hell are you?!" When Dad had a second back surgery, it was sandwiched between a fishing trip with Horner and Betty and the clam season. Saying that my mother and father were enjoying an active retirement would have been understating it. It’s no wonder that the first glimmer of Alzheimer’s was lost in the commotion.

The Doctor was a product of her Scandinavian, South Dakota upbringing. She was a good housekeeper from the "cleanliness is next to Godliness" school of thought. Denial was her chief coping mechanism. Complaining was a taboo. And she was seldom depressed, believing that one should just get up and get going when feeling blue. Apart from that, however, The Doctor was cheerful and enthusiastic on her own, choosing to be happy amid nearly anything. For example, Mom had hammer toes, perhaps the result of poverty and poor-fitting shoes as a child. As a result, on at least eight toes she had multiple corns. She treated these regularly, but they always came back. Having never heard a complaint, I didn’t know they hurt until I was an adult, and a podiatrist told me they were painful. What I did know was that good fitting shoes were extremely important, right up there with cleanliness. While she could have been quietly sedentary with this problem, she was not. The Doctor’s idea of a treat was a brisk walk outdoors.

Finding the beginning of Alzheimer’s is like trying to catch a cloud. One is never sure when it is found. While hindsight may be 20/20, it doesn’t help much when trying to discern something barely there. Who can find the true beginning of Alzheimer’s? We all have moments of forgetfulness, for example. So which ones signify the onset of disease? We all have times of malaise, small depressions, and times of upset. When are these symptoms of something larger? From 1982 to 1985 there were traces of Alzheimer’s, I believe, in Mother. Any one thing by itself was inconsequential. Taken together as a whole, they began to form just an impression that something was not quite right.

There was the family reunion in Spokane in 1982 when The Doctor didn’t recognize Pee Wee. The loss of tact with her sisters. The sense that
some in the family had that Mom was unhappy. The problems Mary Lou reported.

All her life The Doctor was very determined to make the best of things, to put on a happy face. The years of alcoholism had been glued together with her determination. In the early- to mid-1980s, she even told one of her dearest friends, Joan Reiter, that she literally got up each day and consciously put on a smile. She told Joan what a horrible thing it would be to lose one’s mind, that she would hate to be in an accident or have a stroke and end up helpless with no control. She feared becoming a burden. Joan remembers the conversation because Mom got lost driving back from Joan’s home that same day.

Once when my Aunt Babe and Uncle Larry visited Mom and Dad, driving all the way from El Paso, there was no coffee in the house. In a Scandinavian home this would be like not having your head attached to your neck—inconceivable. Hours later, the coffee turned up in some remote spot. Everyone thought The Doctor had played a joke. In hindsight, it might have been that Mother put the coffee away in an unlikely spot and then couldn’t find it. It is not uncommon for people with early Alzheimer’s to seem to be hiding things, when in reality, they are just forgetting where they put them—and they have put them in the wrong place!

Other characteristics began to change. I visited Mom a few times a year. I was noticing that the house was often messy. Over time it seemed to get messier. I asked Mary Lou about it, and she assured me that it was because she and I weren’t around to clean for Mom anymore. Having a more distant perspective, I wasn’t so sure.

In 1984 Dad had seven by-passes done on his heart. I left Ralph and my girls at home and spent several days with my parents. I stayed with Mom while Dad was in the hospital and then stayed a couple of days after Dad got home. I noticed nothing in particular about Mother. I was more focused on Dad, of course, but generally Mom seemed to be functioning normally.

But by the end of 1985, Dad was noticing that something was wrong with Mother because he was frequently asking me if I thought she looked thin. When I said I thought she looked about the same he would drop it. But every time I saw my parents for at least a full year after the heart surgery,
Dad would ask again, "How do you think your mother looks?"

By the end of 1985, my parents’ relationship with Mary Lou was broken. And The Doctor had sent out Christmas cards twice. Some friends still didn’t get a card.
Chapter 3

1986

No one remembers the exact day Mother fell on her way out of the suburban library she frequented. It was in the spring. She hit her head and banged up her face pretty badly. Dad would probably mark that event as the beginning of Mother’s Alzheimer’s. He sent her to the doctor’s office more than once about it and complained to me that he was not sure she remembered why she was at the doctor’s office in the first place. I thought this was just Mother’s way—a bit of denial and a lifelong habit of putting a happy face on things. The physician would ask her how she was, and she’d say, "I’m great!" Babe later told me that around the time of the fall Mom told her she’d had periods of blackouts—times when she remembered nothing. She knew something was wrong, even if the rest of us were just wondering about it. It was early in the summer of 1986 that I had visited my Aunt Dagny and she had asked me, "Do you think your mother is happy?" Neither of us could pinpoint a cause for unhappiness.

August of 1986 brought Mom’s 70th birthday. A party for her was given at Homer and Betty Schmitt’s. They lived in a brick house at the north end of Seattle. Their home also had a beautiful view of Puget Sound with a patio in back of the house. The party was on the patio, but there was a little dancing in the kitchen. Dad and Homer were constantly joking back and forth, never failing to give someone a fit of giggles. All the Doctor’s long-time friends were there. Pee Wee and Fatty came from Denver and Boise respectively. Aunt Dagny wasn’t well enough to make the trip, but Aunt Babe and Uncle Larry came from Texas. It was a great surprise to Mom, and she was thrilled.

In September when my parents came to Spokane for a visit, Mother and
I took a walk together through a nearby pine wood, just the two of us. The Doctor repeated the same conversations over and over during a short half-hour walk. She asked the same questions time and again. When I got back to Dad, I cornered him and told him to get Mom to a doctor and to go in with her, so she couldn’t forget anything.

Looking back, it is hard for me to believe how blind I was. But the incidents I’ve pieced together now were just widely separated events, only traces of a serious problem. To the reader, they seem unnaturally close together. These few incidents happened over a span of four years, and I did not have all the pieces at this early stage. For example, the incident with Mom not recognizing Pee Wee wasn’t told to me for years. Babe didn’t tell me until years later that Mom had said she was having memory lapses—what she called "blackouts." Mom’s friend, Joan, related the incident of getting lost and worrying about losing her mind to me many years later when I told her I was writing about The Doctor. I must admit, I was never able to pin down a problem until the walk and repetitious conversation in Spokane.

Dad did go in with Mother to the doctor. Some tests were done to rule out a stroke. We did not get a definite diagnosis that year, but the physician told Dad that he suspected Alzheimer’s. He told Dad if there were any trips he had been putting off, now was the time to go.

Tom’s life had turned around quickly after he sought help for his addictions. He married Teri, and by the fall of 1986, they were expecting their first child. Dad and I struggled over what to do about the upcoming birth of Tom and Teri’s child. Mom had her heart set on going to Anchorage to be with them when the baby came at the end of November. Since Mom was having times of total clarity and only very occasional periods of forgetfulness, Dad decided to say nothing to Tom and see if Tom even noticed. Tom had been told nothing about Mother except that she had been involved in a fall months earlier and had gone to the doctor to rule out a little stroke.

It was a mistake for Mom to go. Being away from home brought out the worst of symptoms. Mother called Teri "Denise" (her other daughter-in-law) the whole time she was there and drove Tom wild with repeated conversations. Tom called to ask, "What the hell is wrong with Mother?!"
Around this time there had been news reports of a man who shot his wife who had Alzheimer’s. Tom let me know his sympathies were with the man.

One of the things that began to develop at this early stage was a symbiotic relationship with Dad. As Dad’s physical health declined, Mom’s mind declined. Dad could tell Mom what to do. He could go through the steps of getting something done with her. Mom could do it. As the disease progressed, Mom could not think or choose a course of action. Dad became less and less able to do physical things. But as a team, they operated pretty well for several years. Dad was the brain and The Doctor, wonderfully fit and exercising daily, was the brawn. If the bridge club was being hosted, for example, Dad might say, "Let’s go downstairs and get the card table." Together they would go to the basement, and when they got there it was Dad who knew why they were there! He’d give The Doctor the card table and perhaps he’d take a chair. Together they would walk back up and put these in the living room. Then down they’d go again, with The Doctor returning with two chairs, while Dad carried one. This symbiosis continued and deepened as time went on. It was fascinating to watch the natural development of it between the two of them.

By the end of 1986 the immediate family knew there was a definite problem. Homer and Betty had been told that there was a problem. My parents’ closest and lifelong friends, they also were noticing some different behaviors. No one else really knew. Dad was afraid that, if he told people, they would be uncomfortable, and he would lose his friends. When Mother was in groups of three or more people, she could easily hide it. In situations where conversation flowed along, her symptoms did not appear at all. She still played cards fairly well, and she still paid the bills. She still functioned in her home with meals and upkeep, except it kept getting messier. Of course if anyone wanted to know how she was, she would tell them she was wonderful. Couldn’t be better!

None of us, friends or family, had any idea of the magnitude of the problems we were facing. Little did we know that the kernel of a solution was buried in a family story I’d entertained Aunt Dagny with on my visit that summer.

After we left Beacon Hill, Mother had worked for years for a man named Richard Yarrington. He owned a funeral home on the outskirts of
the south end of Seattle. Of course, Mom had prior experience in the funeral business. She had a childhood laced with acting as mourner among her pioneer siblings on the plains of South Dakota. For Mr. Yarrington she was bookkeeper and office manager. She also got to know many a bereaved widow and widower, undoubtedly because she was such a sympathetic listener. She would naturally cry. She came home regularly with a high-pitched lecture to us about how to behave when she died. It went something like this: "You do not honor a person when they die by fighting over his things. I am going to leave everything I have to charity just so you won’t have anything to fight over when I am gone! Why, I see these people who have lost their dear mother and all that they think about is whether Susie gets the hutch or whether Steven should have it. I won’t have my family fighting over my things! Steven won’t speak to Susie any more and WHY?! Well it’s all about MONEY!" She could go on like this for quite some time, talking about people we didn’t know and driving home her point. My aunt, facing her own mortality, chuckled and agreed heartily.

Unfortunately, Mom was partly "gone" years before she actually died. Scattered over three states, her family had suffered through alcoholism, bankruptcy, divorce proceedings, drug addiction, serious illnesses, and rifts. There was a husband who had "beaten" alcoholism in a John Wayne sort of way, that is, without help or much analysis. There was a daughter, Mary Lou, who lived near her with whom she had a broken relationship. Another daughter stayed in touch from the other side of the state, somewhat as detached emotionally as she was physically. She had two sons who had established themselves in two other states. John was in Idaho. Tom—who was crawling out of addiction—was in Alaska. And she had a disease hiding in her future that would force her dependency upon this unlikely group as it threatened to tear all memory from her ever curious mind and to rip all dignity from her.

But we had been well-coached. When Mother "left" us, we had to figure out how to pull together, and we knew it had better be without fighting. We had to take good care of The Doctor. This is her story.