

This over-the-shoulder view of Paul caring for his wife, Judy, tracks events through the seven stages of Alzheimer's with takeaways for the new caregiver. Their love bond helped them through some of the hardships created by this disease.

**Caregiving:
An Over-the-Shoulder View of Caring for a Loved One
Through the Seven Stages of Alzheimer's
By Paul J. Bourgeois**

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Caregiving

*An Over-the-Shoulder View of
Caring for a Loved One Through
the Seven Stages of Alzheimer's*

A Love Story



Paul J. Bourgeois

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Names of doctors, caregivers, and other professionals have been changed.

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Author's Note

Why I Wrote This Memoir

Yes, my Judy is gone, and I still grieve her loss with sadness. Watching a once so vibrant, self-reliant, and lovely woman struggling through what normally were routine daily activities pulled at my heartstrings, but we survived those days together. After her diagnosis, I pledged to myself to make her journey as peaceful and painless as possible until the end, but that end would be her death, nonetheless, after seven and a half years. Poignant images of her last days still linger, but memories of our lives together now overshadow her passing.

Immediately after her diagnosis, I searched for information that would help me prepare for what lay ahead. The Alzheimer's Association's webpage (alz.org) provided information about the physiology of the disease, the characteristics of each of its seven stages, and resources available to help provide care, but that's not what I was looking for. I felt a need to look over the shoulder of someone who traveled that journey before me so I could anticipate what to expect. Perhaps I could come up with better solutions.

Having failed to find that view of someone else's journey through Alzheimer's, I read seven memoirs written by other caregivers, each with a unique personal story to tell. Six of those caregivers placed their loved one in assisted living or a nursing home for the final two years. That's when the real challenges began.

As a contrast, my memoir details events on our journey through Alzheimer's with each scene positioned within its respective stage of the disease. Reflections on this experience illustrate how they affected our lives, and the lives of our children, grandchildren, and friends. I tell about the mistakes I made, with possible alternative approaches, to help the new caregiver develop the tools to deal with what lies ahead. This over-the-shoulder view should help a new caregiver anticipate similar situations, and how to best prepare to meet them.

My top-level definitions at the beginning of each stage, taken from the Mayo Clinic book, *Mayo Clinic on Alzheimer's Disease and Other Dementias*, present a helpful roadmap to the new caregiver. Due to the unique aspect of the disease for each person with Alzheimer's, the timing of individual events that I present may not reflect the specific stage for that same event, or similar events during another's journey.

Since Judy's and my love relationship played such

Caregiving

a significant role in our journey together in ameliorating the unpleasantness we faced in the latter stages of this journey, I begin this memoir with a prologue to illustrate the origins of that bond.

Prologue

I ran out of tuition money for my junior year at Loyola University in New Orleans and took a job working as an extern at the US Public Health Service Hospital on State Street, which was walking distance from the university. The hospital campus looked like a military installation with its gate-guarded entrance and doctors' quarters along the red-brick fence around the installation. I had a room on the third floor of the three-story building between the hospital and the doctor's quarters that housed nurses and externs.

As we crossed the street to our quarters behind the hospital after our final overtime shift during Christmas break, where we pulled medical records for the next day's appointments, Bob, my friend and part-time coworker, stopped and faced me.

“You wanna go on a double date Friday evening?”

“Sure,” I said. Since I seldom had money for dating, I didn't have a girlfriend, so I needed to find a date.

#

On Friday afternoon, as I crossed the quad from the library on my way to Marquette Hall, the main building

on campus, heading for my three o'clock history class, Bob sidled up beside me.

"Meet me in the lobby at 6 p.m.," he said.

I stared at Bob. Our date had slipped my mind. I needed to get a date, and fast, or admit to Bob that I had forgotten. My history class was my only chance. Since mostly freshmen signed up for American History 101 and I was a senior, I didn't expect to know any girls taking this course. I had to try.

I took a seat in the middle desk of three in the last row, where I could see anyone entering the classroom. Strident laughter caught my attention as two girls strolled through the doorway, each cuddling a large history book. The one in the lead, Judy, I knew vaguely from my French 201 class two years earlier; the younger girl I didn't recognize. Judy was wearing a classic green dress that matched the color of her eyes and accentuated a much thinner waist than I remembered. Well-coiffed red hair framed her round face, giving Judy an air of quiet elegance. Chic is the way I saw her. She seemed more mature than the girl who had sat next to me in French class.

I held my breath as she approached and stopped at the desk to my right, then sat down; her friend chose the one to my left. I caught a pleasing waft of Chanel No. 5 as Judy's green eyes flitted discreetly over me. My heart raced. She looked like she would say

something, and then the girls continued their conversation around me as if I didn't exist. Judy's soft, lilting voice sounded like sweet music. Thoughts of possibilities crowded out any ideas of taking notes during that lecture.

Inserting myself between Judy and her friend as we walked downstairs after class and exited Marquette Hall, I faced Judy.

"Would y'all join me in the cafeteria for a Coke?" I asked.

"Yes, thank you," Judy said with a demure smile.

Stephany, Judy's friend, followed as I escorted them to a table near the door and went for Cokes. *Gauche to ask Judy for a date in front of Stephany*, I thought, *but I will if I have to.*

Two WWII Army buildings fused together formed the spacious cafeteria, which had become the social gathering place for students during free periods and the source of meals provided for students with meal tickets. The cafeteria line extended from the right side of the building and across the front. The drink counter stood behind me to my right. I studied in the cafeteria when conversation in the library got too bothersome.

I returned with three Cokes and placed one in front of Judy and another for Stephany. Her friend took one swig from her glass, whispered a few words to Judy, and stood up facing me.

“Daddy’s sending the jet to pick me and my brother up,” Stephany said. “He wants us home for the weekend. Tim’s in Tulane medical school.” She strutted for the door and out of the cafeteria.

I looked at Judy, facing me with an inquisitive expression on her face. *Now what?* it seemed to say.

“Would you join me for a dinner date this evening?” I asked. From the surprised look on her face, I knew she’d say she had plans. Then, a sweet smile spread across her lips.

“I’d love to,” she said.

I let out a breath. I had a date! I sat back in my chair.

“I planned to go home for the weekend,” she explained, “but decided to stay and study. You know, start the semester off on the right foot.”

“We’re doubling with my friends, Bob Gorski and Aimee Everhart.”

“I know Aimee. A language major, right? French, I believe.”

“Pick you up at six-thirty. How do I find you?”

“I’m in the dorm.” She gave me the address.

#

Bob chose the restaurant, Kolb’s, and made reservations. Kolb’s was a famous restaurant in New

Orleans on the wrong side of Canal Street, across from the French Quarter; it reflected nineteenth-century old French design with black wrought-iron filigree across the second- and third-story balconies, a New Orleans trademark. Inside, dark wooden shelves held an impressive array of brightly colored German beer steins, adding a Teutonic ambiance to this Bavarian tavern.

“This place is beautiful,” Judy said. “You come here often?”

“My first time.”

On that first date, I didn’t question Judy about her personal life in front of Bob and Aimee, so I didn’t learn much about her that evening. As I escorted her to her front door, I hesitated, finally mustering the nerve to speak. “Can I see you again tomorrow?”

“Sure,” she said. “I’ll be here all weekend.”

#

The next evening, I climbed the shallow steps onto the porch and glanced through the curtained window for signs of life inside. Abruptly, the front door opened, and Judy slipped outside, closing the door behind her.

“Hi,” she said.

I stepped off the porch. “The Saenger’s showing *Sweet Bird of Youth* with Paul Newman,” I said. “Do

you mind taking the streetcar? Parking can be such a problem on Saturday evenings near Canal Street.”

“I like riding streetcars. I get to see parts of the city I wouldn’t otherwise visit.”

We got off the streetcar at Canal and walked up the street to the Saenger Theater. As I sat next to her and the movie started, the warmth of Judy’s body gave life to emotions I didn’t know I had. Halfway through the movie, I took her hand in mine and felt a gentle squeeze back. Or was that my imagination?

We walked back up Canal Street toward the French Quarter. “Café du Monde for coffee and beignets?” I asked. I spent a lot of time at the cafe during my college days.

“Okay,” Judy said.

At the corner of Bourbon and Canal, the entrance to the French Quarter, a small group stood around a pushcart shaped like a hot dog bun with two wieners sticking out each end and mustard dripping down its side. The strong aroma of steaming wieners made my mouth water.

“How about hot dogs instead of beignets?” Judy asked. “I love hot dogs.” Her eyes met mine. “You’ve got to be short on money after last night at Kolb’s. I can pay for my own.”

“Oh?”

“Not to worry! I have a job now. Interviewed at the Sears on Baronne Street last month. Big surprise! Personnel called last week with a job offer.”

Her mentioning Sears on Baronne Street reminded me of the two tires I’d bought for \$2 each from the huge stack of discards. I booted the blowout holes and stuffed my old inner tubes inside to keep my jalopy on the road.

“What you want on dem dogs?” the vendor asked.

Judy turned to me. “You having onions?”

“If you do.”

At the end of Canal Street, we sat on the steps to the pier, munching our hot dogs and watching the Canal Street ferry dock. Cars from Algiers across the river rolled off, and others lined up for the return trip.

“Have you ever taken the ferry to Algiers?” I asked.

“No.” Her eyes washed over me.

“Let’s do it,” I said.

We bought tickets, boarded the ferry, and sat on the wooden bench at the highest point allowed for passengers. I reached my arm around Judy’s shoulders as the boat churned into the main river current, then cut diagonally across the brackish water toward the other side. I snuggled closer to Judy as we watched the turbulent wake in the murky water. The ferry docked, offloaded, and an agent came and forced us off the ferry

to get tickets for the return trip. I hardly noticed the crossing for the trip back to New Orleans.

The last St. Charles streetcar from Canal Street let us off in front of Marquette Hall, and we walked the short distance to Judy's dorm. Facing Judy on the porch, I wondered about the protocol for stealing a kiss on our second date. The Catholic seminary I attended for high school hadn't prepared me for moments like this.

Judy faced me, her head tilted with an expression that said, *Well, whatcha gonna to do now?*

I slipped my right arm around her waist and drew her to me, half expecting her to jerk back. Instead, the warmth of her body pressed into me, igniting new feelings I had not met before. Her fingers held my head close as the soft warmth of her lips touched mine.

My life had suddenly turned an unexpected corner as I stood on the dorm porch, holding Judy in my arms. I couldn't think of any other place I'd rather be at that blissful moment.

Judy stepped back. "Would you like to come inside? Everyone's gone for the weekend," she said.

The impropriety of entering the house unchaperoned with Judy didn't enter my mind. She didn't want that evening to end any more than I did.

In the lounge, I positioned a chair opposite the sofa and sat facing Judy.

“I’m from Toledo,” she began. “We moved to Hammond after my freshman year. I went to Chatawa, near Jackson, as a boarder. I was home for the weekend during the last semester in my senior year. At dinner that night, I announced, ‘I’ve been accepted to Loyola.’ I’ll never forget the look on Daddy’s face.”

Judy was giving me her life story in a gush of words. I wanted to hold her close as I listened to her soft voice.

“‘We can’t afford to send you to Loyola,’ Daddy said. I was crushed. When I called Loyola admissions to tell them that my family couldn’t afford to send me there and to give my slot to someone else, a recruiter invited me in for an interview. I didn’t know why. The administrator offered me a full-ride scholarship.”

“You must have an excellent high school record.”

“And lots of extracurriculars.”

“If you had been on campus for the past two years, I’d have seen you.” I looked into her eyes. “Did you drop out?”

Judy’s face flushed red.

“I’m sorry. I didn’t mean to pry.”

She looked at me. “I needed a 3.0 GPA to keep my scholarship. I got a 2.9. Can you imagine? Losing a

scholarship to Loyola University by one-tenth of a point! And over Theology, no less! I took a job editing the Hammond newspaper to save money to come back to Loyola. But enough about me. Tell me something about you that I couldn't find out by asking around campus."

I leaned back in my chair. "I have an identical twin brother, Patrick—Pat. Born on St. Patrick's Day. Looks just like me. We've had lots of fun being twins. He's at Notre Dame Seminary on Carrollton Avenue studying to be a priest."

The look on Judy's face framed her next words. "I've got to meet this Pat."

"Why?" I asked.

"Having a twin that's going to be a priest says a lot about him and about you."

Judy and I spent every spare moment together during that semester and married on June 9, her twenty-first birthday. After graduation, I joined the Air Force to avoid the draft. Our strong love bond helped us through some difficult times in those early years. We reared three children as I pursued multiple careers. Little did we know at the time how much this strong bond that got stronger with each passing year would serve us in the final stage of Judy's life.

STAGE I: BEFORE SYMPTOMS APPEAR

Preclinical Alzheimer's begins when early indicators appear ten to fifteen years before symptoms that lead to a diagnosis are noticeable. Close relatives, friends, and even medical professionals usually misinterpret or miss these early indicators.

At the time of this writing, researchers consider slowing the disease's advance or curing it to be unlikely once neurons in the brain are destroyed. Future medications to prevent Alzheimer's or slow its progress will be most effective in this first stage.¹

*For Judy, pre-diagnosis dates back to 2004, **nine** years prior to real symptoms.*

¹ The definitions for each stage of Alzheimer's in this memoir are edited versions from the Alzheimer's Association web page.

1. The Early Signs

Judy experienced early memory issues nine years prior to her Alzheimer's diagnosis, but they seemed trivial at the time.

I had just passed my sixty-fourth birthday and was planning to retire in a year; looking ahead, Judy and I visited several over-fifty-five communities in Northern Virginia as a first step toward retirement, but when we didn't find anything that pleased us, we stopped looking. Then, Judy saw an ad in the *Washington Post* Sunday real estate section for a new development at Regency at Dominion Valley in Northern Virginia that she liked, and she wanted to take a look. As we neared the subdivision entrance, road construction told us that the Dominion Vallen community was expanding.

The entrance to Regency dead-ended into the number-one golf course's tee box. Tall trees skirted the fairway's left edge, and verdant lawns and bright-colored pansies adorned empty spaces along the entrance road and around the model homes. We drove along the few roads that were open to look at houses.

"Now, this is more like it," Judy said.

In the Regency sales office, a three-dimensional area mockup on a large table highlighted lots available and those about to become available.

“Let’s pick a lot that will have minimum traffic as the subdivision grows,” Judy said.

We had owned five houses over the years, and we both had a good idea about what we wanted in our retirement home. The road she pointed to looped around to parallel the main drag, which promised that the only car traffic on our street would be limited to those who lived there.

“We’ll take this one,” I said to the real estate agent, pointing to the middle lot in the group.

We had four different floor plans to choose from; we selected the model home with a master suite, a large den, separate living and dining rooms, a kitchen, a bath on the first level with two large bedrooms, a private bath, and a sitting room in the loft. The upstairs living space would accommodate family members and friends we expected to visit during our retirement. We signed the contract in June 2004 for our new home, which would be completed in April 2005.

#

Three weeks after we signed the contract for our new home, we drove out for a looksee at our lot. As we drove along the dirt path that was euphemistically

called a road, I checked the stakes marking the lots and found ours. We both stared at what had been a bare piece of land; we were looking at a concrete slab, freshly poured, with two piles of prefab home construction components stacked behind it. *This house could be delivered early*, I thought. I needed to get our Centreville home on the market for a quick sale so we could move into our retirement house.

At home that evening, I drew up an action-item list of what I needed to do before putting our house on the market and decided to start the repairs the next evening. I left the list of supplies I needed for the evening's work on the kitchen table so Judy could do the shopping, which she usually did while I was at work.

When I got home from work the next evening, Judy was sitting in her den chair watching TV, and my list stared back at me from where I had put it on the kitchen table. Judy had not touched it. In prepping our four previous houses for the market, Judy had been an equal partner. She shopped for paint, brushes, rollers, turpentine, and anything we needed for that evening's tasks while I was at work. In the evening, we worked side by side on the project for the day, and sometimes she took the initiative to do a task while I was at work. I thought something must be wrong.

"Are you okay?" I asked.

"I'm fine," she said, and continued watching TV.

I changed clothes, went to Lowe's to pick up supplies for the evening, and worked alone. In the days that followed, Judy didn't shop or help with the repair work in Centreville, a clear deviation from how we had worked together in the past. Judy had symptoms of arthritis, so I chalked it up to aging.

Taken in isolation, not helping with repairs was a behavioral change that didn't cause me concern. I later realized Judy had forgotten that she had ever helped with work to prepare our earlier homes for market. I now see this behavior change as her first early indicator of Alzheimer's.

#

By December, I had finished projects inside the house and was about to move outside into the yard, but I took a break to attend a Christmas party at my boss's house. Judy and I enjoyed some heavy hors d'oeuvres and then made our rounds talking to other couples. Tired from standing, Judy found a sofa in the den at the back of the house where her friendly face invited conversation.

"Boy, do my feet hurt," the woman sitting next to Judy said. "We spent the whole day house hunting—my husband and me."

"And where are you looking?" Judy asked.

“Today, Great Falls. Tomorrow, we’re gonna try Centreville. It’s further out, but more affordable.”

Judy gave the woman a wan smile. “We’re about to put our house in Centreville on the market,” she said. “Would you like to come by for a walkthrough? You could get some idea of what’s available in the Centreville area. No strings attached.”

“Why are you selling?”

Judy nodded in my direction. “My husband, Paul. He’s retiring next year. We’ll be moving into our retirement home in April.”

The next day, the couple visited our house and spent considerable time in the master bedroom discussing furniture placement. On the sidewalk in front of the house on their way out, they both commented on how beautiful the place looked. (He later commented to my boss that “the house was impeccably clean,” a testament to Judy’s housekeeping.)

“How much are you asking?” the husband asked.

I mentioned the price Judy and I had discussed. The couple huddled together for a moment and made an offer on the spot close to the price I had quoted. We accepted.

Judy sold our house before we put it on the market and saved the realty fee in the process. She then

orchestrated the sale herself. That closing went smoother than any of the four homes we had previously sold. How could someone who had succeeded in pulling off what Judy had done be suffering cognitive impairment? One thing I learned early on about Alzheimer's: On any particular day, things appear perfectly normal, and then, out of the blue, comes the unexpected.

We scheduled the closing on our new home for April 15, 2005, and began planning for the move. To decorate our earlier five homes, Judy had taken advantage of sales and produced impressive interiors on a tight budget. This time, we had money in our account from stock options I had cashed in prior to retirement, which gave us a comfortable margin to spend on the interior décor without using savings.

Days before closing, Judy told me, "I signed a contract with Next Day Blinds to make window coverings for the master bedroom and the living and dining rooms. I'm having wooden shutters installed in the den and the breakfast nook, and on the sliding door to the patio."

"Shouldn't you have waited until after we closed to sign that contract?" I asked. "What if there's an issue that delays closing?"

“Installation is set for Saturday, the day after we sign the papers,” Judy said.

The closing went on schedule, and everything was finalized.

In the living and dining rooms, Judy had put a sky-blue two-inch strip across the beige curtain valence that matched the color of the walls. In the master bedroom, a detailed floral design in the queen-sized bedspread and pillow coverings was repeated in the custom curtain set across the triple window. Judy had decorated our previous homes beautifully, but what she accomplished in our new home reflected superb taste.

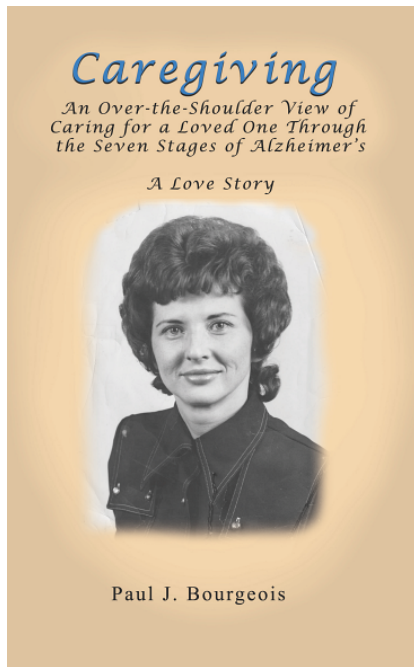
And then, the bills for the decorations came in, and I was shocked. Judy had gone first class all the way. Neither of us ever made such large purchases without consulting the other. That was out of character for Judy, but I didn’t see a connection between that and dementia. Much later, I decided that she had forgotten the process that had been acceptable to both of us over the years.

That deviation from our norm was another early indicator of her disease that, in a future scenario, might call for follow-up action. At some point, these early indicators will justify early treatment considered necessary for new medicines under development to work. Researchers seeking cures for Alzheimer’s, or to slow its progress, believe that once neurons are

destroyed that enable communication between elements of the brain and the rest of the body, they cannot be repaired. Thus, recognizing these early indicators and reacting to them will be critical to early diagnostic testing for new medications to be effective.

On April 18, 2005, we moved into our retirement home in Regency at Dominion Valley in Northern Virginia, and in September of that same year, I retired and took to playing golf.

I recommend the book *Mayo Clinic on Alzheimer's and Other Forms of Dementia* to enable recognizing the early symptoms of Alzheimer's. Brain changes associated with Alzheimer's disease can lead to early indicators, which will be critical for early diagnosis, justifying treatment with new drugs that cure or slow the progression of the disease.



This over-the-shoulder view of Paul caring for his wife, Judy, tracks events through the seven stages of Alzheimer's with takeaways for the new caregiver. Their love bond helped them through some of the hardships created by this disease.

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