

THE GEOGRAPHY OF MEMORY

A Pilgrimage
Through Alzheimer's



JEANNE
MURRAY
WALKER



CENTER
STREET

New York Boston Nashville

Some of the names of people in the work have been
changed to protect their privacy.

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PREFACE

I wrote this book because I believe the news about Alzheimer's is more hopeful than what we hear on the street. And it needs to be told. Alzheimer's scares Americans quite literally to death. The Alzheimer's Association claims that between 2000 and 2008 deaths from Alzheimer's increased by 66 percent while every other major cause of death decreased. It's risen to the sixth leading cause of death in the United States. By 2050 the incidence of Alzheimer's is expected to quadruple worldwide. As a recent op-ed in the *New York Times* has argued, fear of the disease causes children to abandon their parents, and parents to consider suicide, rather than living through dementia. What a parent has to gain from being cared for by her children may be obvious, but it's less clear what the child has to gain. Nevertheless, I learned that to stay and struggle through Alzheimer's is to reap gifts that may not come any other way.

One of the surprising gifts of those years was that I began to understand even the most wacky of my mother's comments; I gained a new appreciation for dementia victims. In fact, often my mother's conversation seemed fresh and surprising. Some of her comments were funny, though I felt guilty about laughing. Slowly it dawned on me that what she said wasn't random, though it sometimes sounded that way. In fact, all her life she had sprinkled so much metaphor around her speech that my

father often teased her about it. Toward the end she often drew her metaphors from her early life. A lot of what she said was hard to decode. But because I knew her story, I could often guess what she meant.

Mother, like all of us, carried her former selves inside her, almost as if they were characters in a play. During her final decade, her earlier selves would emerge. Not that I could predict which Mother would speak next. She might be eight years old, talking to her grandmother (me), or a school nurse, at forty, speaking to her high school principal (me), or at twenty, explaining (to me) the odd thing one of her gentleman callers had done that day. As she verged into dementia, her earlier selves came and went at will. I sometimes thought, now I have several mothers.

As I spent thousands of hours with her, I began to recover my own past. I had never reflected at length on my early life: I had forged a path straight through graduate school to a teaching job, which I combined with raising children, keeping house, and writing. I was always casting myself into the future, reinventing courses, writing in new genres, applying for grants, scanning the horizon. The past got crowded out. Maybe that's what I wanted. Why should I hang myself on the hook of my past, especially such a traumatic past as I'd had? For me the last decades of the twentieth century were such razzle-dazzle, jaunty, surge-forward years.

And then I had to slow down to take care of Mother. Ironically, as she lost her memory, I gained mine. During the hours and hours I spent with her, scenes from earlier years that I had entirely forgotten leapt back so forcefully that they almost seemed to be happening in the present. I began to comprehend my own history in a fresh way. I saw how I had defined myself against Mother, how hard I had to fight to get away from her,

and what it had cost us both. This unexpected recovery of my own memories that came during Mother's Alzheimer's calamity became one of the most spectacular gifts of my life.

I also developed a deep bond with my sister. As the two of us cared for our mother, the connection between us blossomed into a remarkable friendship. This friendship is not without conflict. In fact, our last decade with Mother might be called a difficult spiritual journey. But looking back, I see that it *was* a journey, an unpredictable one with abrupt declines, giddy periods of recovery, and, of course, plateaus. In emergency phone calls, through violent differences of opinion, from very different points of view and different regions of the country, my sister and I honored one another as co-partners. We came to know one another better and appreciate one another more.

And even after Mother was almost incapable of talking, she was teaching me about life and death. What she had to teach was not always what I wanted to learn. In our society, where cosmetics companies make billions helping us eradicate wrinkles and other signs of aging, news about the ugly twins, aging and death, is not welcome. Our Disneyfied culture barely acknowledges that they exist. But in the end, it's better to know about them. What we suppress pops up to govern our behavior. If we can't bear to look at death, it rules us. It begins to manifest itself in ongoing anxiety, to spring up in nightmares. To face it squarely can be freeing. To think about death can change the way a person decides to live. Taking care of Mother gobbled up vast quantities of my life; watching her change was agonizing. But it left me different, wiser, better.

I received one final gift. Utterly lost on a dark Dallas expressway at two a.m. one terrifying Thursday morning, I saw that I was not just slogging through what seemed like endless repetitive years of horror. I was on a kind of pilgrimage. That long

pilgrimage with my mother and my sister taught me—perhaps it taught all three of us—spiritual disciplines. Among them I count prayer, hospitality, patience, forgiveness, humor, imagination, meditation, silence, empathy, and letting go. For much of that long slog I wasn't thinking in religious language. But these spiritual disciplines and gifts appeared and reappeared, braiding their way through our daily experience, lingering like a faraway melody on some of the darkest mornings. These graces came very slowly and at the beginning they had no names. It is only now that I am beginning to identify them.

Alzheimer's is bleak. It is. But it's not all horror. My mother's last years reveal that for all the heartache, there can still be joy and laughter, insight and love. In this book I have tried to focus on more than just the catastrophes the disease brings. I have tried to bear witness to and name the gifts that came to us. This naming, I trust, will offer hope to Alzheimer's patients, to their spouses and children, to all the disease has terrorized.

Chapter 1

THE PHONE CALL

Far away, as if through a mist, I hear my husband calling. Swimming up from a dream, I roll over, open my eyes. He's leaning on one elbow in bed, facing me, softly repeating my name. In the milky gloom, I can barely make out his figure.

"What?" I ask. We're in Paris in a hotel room. That much I remember. I push farther down into the warm sheets. I don't get back to sleep easily.

"I think something's happened to your mother," he says.

Sitting bolt upright in the dark, I watch as my husband swabs the floor for his phone. There's a cold breeze leaking in the closed windows. I pull the duvet around my shoulders and press the stem of my watch, which lights up the dial. It's two thirty a.m.

My husband is mistaken, I think. How can he know that something is wrong with my mother? She's in Dallas.

He's jumpy. We're both jumpy after the recent news: that my mother's been in a car accident; that the Christian Care Center is moving her to the Alzheimer's unit; that she needs hospice care; that she has broken her hip.

He sits in bed pushing buttons on his cell phone, pressing

the phone against his ear. The curtains ripple. A monotonous, vengeful January wind whips the trees outside.

"Hi, Rich," my husband says. Rich is my brother-in-law in Dallas.

Silence. My husband looks troubled.

He takes the phone from his ear. "Your mother has died," he says.

I try to believe this, but I don't understand it. I might as well be a stone, unable to feel water pouring over its back. How did he know she was dying? Did she visit him? I wonder. Did he feel her leaving?

He holds out his phone.

I take it.

"We were with her," Rich tells me. "She was asleep. She didn't seem to be in pain. She just never woke up."

With dementia, finally the brain and lungs shut down. But the progress of the disease varies so much with each victim that no one can predict in what month or even what year the end will come. I thought, as her doctors did, that we had many months to go.

Outside, the gnarled treetops boom and crack as they thrash in the wind. When the trees go, I think wildly, everything is in danger. Whipping branches cast shadows against the filmy curtains. My mind keeps slipping its groove, slipping its groove like a vinyl record. Rich goes on talking, this man who has lived through so many emergencies, offering me valuable facts in his calm voice.

"Her favorite aide was with her. And her hospice nurse."

"I'm glad."

I'm *not* glad. I don't feel a thing. But one has to say something.

"You want to talk to Julie?" Rich offers.

"Yes."

“Don’t feel like you have to come home,” Julie says immediately.

“I want to.”

“Don’t you have another week to teach?”

I fumble for the answer.

The program. Oh, yes, she must mean the University program I’m teaching this month in London. How much longer does it run? I can’t remember.

My husband is pulling on his clothes. When he flicks on the light, the massive ornate furniture rears up around us: a walnut dresser, the maroon duvet with a giant green and burgundy and white paisley pattern. He stands at the window, lifting the curtain at one corner to look out. I feel as if I’m watching a movie of someone else’s life.

“How many students do you have?” Julie asks.

“Twenty.”

“You can’t leave them in the middle of the program, can you?”

“I don’t know. I *want* to come home,” I say, hoping I really do.

“I can take care of things here,” Julie says.

By *things*, she must mean the body. The body that held me before I came into the world, the body that held her. She means my mother’s body has to be buried, the final thing we can do for her. My mother looked like a little hollowed-out canoe a month ago, when I last saw her. She weighed barely a hundred pounds.

For almost a decade my sister and I together have taken care of our mother’s clothes, her medicine, her friends, her housing. We’ve gone fifty-fifty, each with different tasks. Julie, who lives close to her in Dallas, makes quick trips to check in with her weekly. She and Rich entertain her at lunch on Sunday. They take care of her finances. I fly to Dallas four or five times a year and stay with her for a week, or part of a week, to wash her clothes, buy her shoes with rubber soles, take her to lunch in a restaurant, encourage her

friends to keep visiting her, bring candy to her nurses, stock her apartment with flowers, whatever needs to be done. For years Julie and I have been phoning and e-mailing one another about what might keep Mother safe and occupied and challenged. As we cluck and fuss over her, we are getting to know one another better, coming to rely on one another.

I understand that this, too, has come to an end. I understand it better than I understand that my mother is dead.

“Promise me something,” I say to Julie.

“What?”

“That we’ll still see one another.”

“Sure,” Julie replies.

She means it, I can tell; I just don’t believe her. Both our lives are monopolized by children and houses and demanding jobs.

“Mother would want us to,” I tell her. “You promise?”

“Okay.”

“Really?”

“Yeah.” But without a crisis, I wonder what will bring us together.

The wind rattles the glass in the windows. It sounds cold and hysterical. My husband is going through the receipts in his billfold, glancing over at me from time to time.

“Can I let you know our plans tomorrow?” I ask Julie.

“Sure.”

“We’ll call the kids and tell them what’s happened.”

“Okay. And if you can’t come home, we really are okay here,” Julie says.

I look at my watch. My mother died on January 27, 2008.



It’s a long night. Time slows down, lengthens out. We sleep fitfully, or rather, we don’t sleep, lying in a semiwakeful stupor

of demonic, distorted thoughts and images. The prayer I have been teaching our three-year-old granddaughter comes to me in the bell-like clarity of Sophia's voice. *O Lord, support us all the day long, until the shadows lengthen, and the evening comes, and the busy world is hushed, and the fever of life is over, and our work is done. Then in your mercy, grant us a safe lodging and a holy rest, and peace at the last. O Lord, support us all the day long, until the shadows lengthen, and the evening comes.*

The evening, I think. The evening means Death.

Chapter 2

THE CHOICE

The next day, charcoal clouds hang low over Paris and the air outside the window of our hotel is heavy and gray. We drink coffee and eat croissants in a neighborhood hole-in-the-wall, while locating an Internet café on our brightly colored tourist map. Then we pull on our hats and coats and gloves and step out into the bitter January wind to search for it. It's Sunday. We called the children first thing. Now we need to e-mail my office to let them know that I need to leave the program. Or maybe that I'll stay.

I need to settle this.

The trouble is, I can't remember the names of streets. A few minutes after I see a name on the side of a building, it's gone. A windshield wiper keeps everything clean and blank in my head. I am supposed to be the navigator, but we wander like homeless people through the damp fog. Finally we notice that we've circled past the same shops several times. We stop in a computer store so my husband can ask for directions in his elementary French, which is better than mine. Then we start out again, in the opposite direction, where the salesperson has told him, in French, to go. Following this route for a mile or so, we turn left

and then right, and then left again, but we find no Internet café. So my husband steps into a stationers' to ask again.

My feet are so brittle and icy that I can no longer use my toes for balance. I feel as if any moment I may topple over. I open and shut my hands inside my gloves to get the blood going. With dismay I begin to recognize buildings. We're looping back toward the restaurant where we had breakfast. It's getting dark and we have wandered for almost the whole day, it seems to me, though when I look at my watch, I discover that it's only eleven. We again hone our attention like zombies to find some Internet café. I must confer with my university administrators. We must decide whether to fly home.

By noon we are exhausted and frozen. Finding ourselves close to Notre Dame Cathedral in surreal darkness, we allow ourselves to be carried along by a stream of worshippers. We drift by the immense flying buttresses, beside the tall stone angels and saints, through the massive doors rimmed with multiple levels of sitting and standing granite figures. Who gets to sit, I wonder, and who has had to stand up in this cathedral entryway for seven hundred years?

In the gloom of the interior, my eyes take time to adjust. Overcast daylight shines through the splinters of stained glass in the great rose window, illuminating points of turquoise and sapphire and cobalt blue. I hang on to these pricks of light with my eyes as we sit down on wooden chairs in the cavernous nave. Notre Dame is a tourist destination, but we are surrounded by French people, mainly, it looks. Each is stylish, with a clever hat here or a distinctive tie pin there or an orange scarf. The man sitting beside me is bundled in a bold black-and-white houndstooth checked coat.

Above us soars the vaulted ceiling, its ribs and barreling

webbed in shadows. Stone gargoyles with distorted lips and bulging eyes leer down from columns and pedestals. They are faces of idiots and fools the stone carvers remembered from the back alleys of their villages. I feel like them, stupid, dumb. But it's not nice to stare. I avert my eyes, then move my gaze to the gigantic altar. I blink dizzily at the golden chalices and ornate boxes.

It comes to me that a great cloud of witnesses really does surround us in this cathedral, spirits of generations. By kneeling here, I can see where they wore down the stone floor. The tall altar candles flicker. Fire endures while the candle gets used up. The spirit is more enduring than the body; that's what the candle says. Oh, images and their poignancy! We sail together, the living and the dead, as if nestled together in a massive ship.

As this congregation of strangers stands and steers through the French liturgy, I think about my mother lying alone in a funeral parlor. Or rather, not my mother, but my mother's *body*, her arthritic, knobby hands, her mouth, her forehead. They've laid out her body in the room where my stepfather was displayed years ago beside Chippendale chairs with striped mulberry and mustard upholstery. The sideboard. The wallpaper. Those funeral directors wanted their parlor to look as much like a living room as possible.

In my daze, I'm jarred by the sound of French droning through the Dallas funeral parlor. Then I recall that we're in a church in Paris. Translating the French, I catch snatches of meaning. *We lift our hearts up to God. It is meet and right for us so to do.*

My mother's spirit left her body fewer than twelve hours earlier. I think with some panic that I'd better consider what that means, while the rupture is still fresh. It feels like being at the scene of a car accident, needing to write down the details. I wonder whether

her spirit is floating between earth and heaven. Such airy existence is new to her. I wonder whether she feels out of place. I wonder whether she is trying to make herself understood to other spirits, trying to make friends on this first day after her death.

And I wonder how my husband knew when my mother's spirit departed her body. What made him wake up soon after she died? He loved her, of course—or rather, not *of course*, because most sons-in-law and mothers-in-law do not love one another. Did she wake him? I wonder again.

But how?

The priest stirs, begins moving his hands, raising the chalice. He's far away, in heavy robes, looking like a magician. At some primitive level, I feel that my mother cannot be dead, because, very simply, she gave me life. My life poured into her and then my body tumbled out into the world. How can I still exist, when the person who caused my existence has died? I hold one hand out and stare at it. I see its familiar jade ring.

My fingers tremble slightly. I fear that I am not doing well, that we have decisions to make, that I cannot afford to fall apart, that I need to do whatever people mean when they say they are pulling themselves together.

When the mass of people rise to their feet and sing "Holy God, We Praise Thy Name," I try to recall the English words: *Holy God, we praise Thy Name; Lord of all, we bow before Thee! All on earth Thy scepter claim, All in Heaven above adore Thee.* As the priest begins his homily, the cathedral brightens the way the sky opens when a cloud passes from the sun.

In that moment I sense my mother. I feel a little frightened and improbably buoyant. I don't know why her spirit has come back, or how. I just know that I am in a French Catholic church the day after mother died, and her presence, like light, falls across me through one of the cathedral windows. It strikes

me as odd that she's here, funny, really, because she was such an anti-Papist. And as the child of German immigrants, she held no truck with the French. But even in the later stages of Alzheimer's she had a sense of humor.



The following day, when I speak with the administrator at my university, she offers me the condolences of the whole staff. They'll be thinking about me, she says. She tells me I should do whatever I need to do. But no, unfortunately, each Study Abroad Program is unique, and there's no one to take over my program. If I leave Europe, my students' program may be over.

"Will they get credit?" I ask her.

"We'll have to figure that out," she tells me.

"They've worked hard all month."

She doesn't reply.



Two days later the students and I climb to our classroom on the fourth floor of our Russell Square walkup, where I meet the Study Abroad students for classes, our feet shuffling on the carpeted steps. The room smells stuffy. I sit on the desk at the front. The students peel off their coats and drop into the chairs. A radiator crackles. In the eaves just outside the windows, birds chirp frugally.

My students' faces glow with the adventure of their recent travels to Rome and Edinburgh and Dublin, where they have gone during the five day break that my husband and I spent in Paris. They laugh and call to one another. They pass around pictures on their cell phones and laptops. They tell jokes and exchange souvenirs. As a group, we've gotten close. Right now would do anything for each other.

I watch them numbly. I have no idea what I will tell them. In thirty years of teaching, I've never felt so dimwitted in a classroom.

Eventually the students notice me. Quiet descends on them gradually, and they settle down slowly the way a bedsheet, after being snapped, flutters to the floor. Several of them turn their faces toward me, a bunch of sunflowers swiveling toward light. In that moment I cannot conceive of how to explain that their London Study Abroad program is over, that they waited tables for two summers to earn money for the trip that now may go down the drain, that they will have to fly home immediately, and they may not get credit.

I know perfectly well that I have the right to leave. It's my *mother*, after all. But if I do, I can't imagine what would happen to these children who have been put in my charge. And besides, I think my mother would want—no, that my mother *does*, actually, *right now*—want me to stay. Didn't she always tell us to finish what we start? If I could ask her and she could answer, she would tell me she doesn't need me in Dallas. She's gone to a better place. She's with my father. Those are the exact words she would use.

So I don't leave my students. The students never learn that my mother has died. On Wednesday morning, my mother is quietly buried in Dallas while I am teaching a class in London.