

A Family Caregiver's Guide to Alzheimer's Disease.

Alzheimer's Stories. A Caregiver's Guide to Mismatched Outfits, Goofy Hair and Beer for Breakfast.

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ALZHEIMER'S STORIES

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A CAREGIVER'S GUIDE TO
MISMATCHED OUTFITS, GOOFY HAIR
AND BEER FOR BREAKFAST.

KAREN FAVO WALSH



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Several names and identifying characteristics of the individuals depicted in this book have been changed to protect their privacy.

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This book is for those who choose the journey.
Special thanks to my tour guide Billie, and my travel companions: Frank, Charlie, Emily and Daniel.

ALZHEIMER'S STORIES

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INTRODUCTION

Do you suspect someone you love suffers from Alzheimer's Disease (AD)? Curious behaviors surface long before an official diagnosis. Is your person hiding your shoes, repeating stories, wandering?

You're not alone. The worldwide estimate by Alzheimer's Disease International is eighteen million people currently have AD. Millions more are caregivers.

Alzheimer's Stories is full of honest, intimate details about Alzheimer's. Its short, relevant chapters provide fast advice to time-starved caregivers. I hope this book helps you find the magic moments hidden inside this incredible disease.

—K.F.W.

ALZHEIMER'S STORIES

CHAPTER ONE

A Slow Descent

“She’s at the top of the hill, about to fall down it.”
— Neurologist’s description of Billie, July 27, 1999

Billie sits back on her heels and squints at the setting Florida sun. Her hand paints a brown line of dirt across her forehead as she wipes perspiration above her gray eyebrows. “I don’t always understand conversations or directions,” she says.

I kneel on the ground next to her. My toddler, Emily, plops down beside me.

“What do you mean?” I ask.

“What I hear isn’t always what people say.” She yanks the weeds around an unruly red hibiscus. “Oh, don’t listen to me. I’m crazy.” She forces a laugh.

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“No, you’re not.” I pull weeds, too. “Your hearing aid should help. Don’t worry.”

Billie stands and brushes dirt off her kneecaps. She shakes her head.

Billie is a retired librarian and one-time preacher’s wife. She and my father-in-law, Frank, have been companions since 1976. Practicing Buddhists, they are former hippies who marched for civil rights, Native Americans, feminism and the environment. Now, they attend museums, lectures, concerts and new restaurants. They spend winter here in Florida, and summer on Saginaw Bay in Michigan.

Emily and Billie wander away from me. Hand-in-hand they stroll across the yard gathering fallen twigs and palm fronds. Sunlight bounces across Emily’s yellow curls and brightens Billie’s tentative smile.

Eighteen months earlier, in May 1986, Billie sat by my bed on the high-risk maternity floor of Bayfront Medical Center in St. Petersburg. Twenty-six years-old and eight-and-a-half months pregnant, I was in the hospital for complete bed rest. Pregnancy-induced hypertension.

My family was far away in Pennsylvania. My husband Charlie had to work all day. Billie’s frequent visits cheered me during an uncomfortable attachment to a fetal monitor, catheter and IV. She delivered books, magazines and a deluxe green and white striped diaper bag. She rubbed my back, told funny stories and assured me our baby would be healthy.

Billie was with me when I left recovery and held Emily for the first time, three days after her birth. A week later,

A SLOW DESCENT

Charlie, Emily and I went home as a new family. Billie cooked meals, babysat so I could nap, and embraced Emily as her own granddaughter.

Now, Billie needs comfort from me. Her expensive new ear piece can't solve her auditory problem. Something in her fifty-nine-year-old brain scrambles information, with or without the aid in her ear.

Four weeks later, Billie loses her high-tech hearing aid. As time passes, the problem becomes more and more serious. Within four years, she misplaces larger objects.

"Billie's at the mall and can't find the car. Can you drive me there?" My father-in-law, Frank, chuckles over the phone.

"Sure, we'll come get you," I say. "I just painted clown faces on the kids, so we look silly."

My five-year-old, Emily, a blonde clown in a tie-dyed sundress and pink plastic sandals leads us into Tyrone Square Mall. Daniel, my three-year-old blue-eyed boy, follows her. They swing their arms and smile at the Saturday shoppers. I walk behind them, next to Frank. The paint spatter in my auburn hair and on my black shorts identifies me as the clowns' escort. Frank's glasses, gray hair and beard don't resemble a clown, but his green socks and yellow suspenders add color.

Our search party hustles through the mall. Daniel stops to press his red clown nose against a glass booth in the concourse.

"I want a pretzel," he says to a teenage boy tying dough in a knot.

"Come on, Daniel." I take his hand. "We have to find

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Grandma Billie. We'll eat later." As we pass Burdines, my eyes lock on the summer business suits in the same way Daniel eyed the pretzels.

At the JCPenney-Dairy Queen intersection, I stretch my neck to view the pay phones in front of the Ritz Camera store. Billie is there, dressed in an Everglades tee shirt and faded jean shorts. A silver pony tail hangs down the center of her back. Only her eyes move as she scans the weekend shoppers for a familiar face. Her Birkenstock sandals stick to the floor in the precise location she described to Frank. "I'll stand by the phone until you get here."

Billie's shoulders straighten when she sees us. A grin replaces her tight-lipped frown. "Well, look who's here! Look at your faces!" She hugs the clowns as if they were away at the circus. Her green eyes fill with tears. "Oh, Frank."

"Don't worry. We'll find the car," he says. "We always park by Dillard's. We'll look there first." He pats her shoulder. Emily and Daniel each grab one of her hands.

Ten minutes later, Billie and Frank reunite with their car outside the main entrance to Dillard's. They follow us home. I paint clown faces on them, too. The face paint can't hide the growing seriousness of Billie's memory loss.

Billie develops coping skills to deal with her impairment. "You're right about that" or "I'll say" serve her in any conversation. Her forgetfulness leads to repetition. During Sunday dinners at our house, Billie repeats herself six times during one meal. We always pretend the story is new.

Her next symptom is wandering. It grows from nuisance to major problem in a year. Billie disappears at the grocery

A SLOW DESCENT

store, the movies and restaurants. Friends and relatives begin to chaperone her on all excursions. We don't lose Billie as often, but we do still lose her.

On a balmy March afternoon, music, food and people mingle in the city's waterfront park. Frank and Billie watch Irish dancers at the 1998 St. Petersburg International Folk Festival. Grills sizzle and grease fryers bubble as gyros, funnel cakes and egg rolls cook under fifty white tents. Sweet and savory smells tickle our noses. A relaxed afternoon turns tense with one question: "Where's Billie?"

Family and friends huddle in a tight circle.

"Where can she be?"

"She's probably watching the bagpipes."

"Do you think she left the park?"

"I hope she isn't scared."

"How will we ever find her? There must be ten thousand people here."

By foot, bike and car we search around performers, families, teenage couples and retirees. Three times we separate, explore and reassemble. It's a futile hour-long search. When we don't know what else to do, we call Frank's house.

"I wondered where everyone was," Billie says into the phone. "What are you doing?"

We can only guess how she traveled three miles from the festival to home.

In July 1999, Charlie, the kids and I visit Billie and Frank at the Michigan house Frank's family built on Saginaw Bay in 1911. When we arrive, they resemble over-weight, sleep-

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deprived zombies. Nocturnal bouts of paranoia and disorientation cause Billie to wake Frank several times every night.

“Billie gets up three or four times a night,” Frank says, “Sometimes she’s frightened, sometimes she’s hungry.” He shrugs. “We probably eat lunch two or three times a day now. I don’t argue when she forgets her last meal was an hour earlier. It’s just easier to eat again.”

Two of Billie’s three grown children live in Michigan. Jenni and her family live twenty minutes down the road in Bay City. Craig’s home is in Ann Arbor, two hours away.

During our visit, Frank, Billie, her kids and I drive into Bay City for Billie’s appointment with a neurologist. Dr. Bong Jung examines her and announces she has Alzheimer’s Disease. He tells us, “She’s at the top of the hill, about to fall down it.”

The next morning, Frank and I join Craig and Jenni in a meeting with a Bay County healthcare worker. We schedule twice weekly visits with a nurse’s aide to help Billie shower. The home health visits end after two attempts. Billie refuses to cooperate.

Throughout Billie’s cognitive decline, Frank is patient and accepting. “Billie doesn’t remember yesterday, and she doesn’t worry about tomorrow. So, what’s the problem?” he asks.

The problem is Alzheimer’s causes absurd and potentially dangerous situations. When Frank has a serious asthma attack, Billie calls 4-1-1 instead of 9-1-1. What will happen when she forgets 4-1-1?

For twenty-three years, Billie and Frank have spent their

A SLOW DESCENT

summers in Michigan and winters in Florida. After Billie's Alzheimer's diagnosis, Charlie and I prepare Frank's home in St. Petersburg for year-round living. We want Frank and Billie near us.

In November 1999, I resign from work. It's a dramatic switch from the fast lane of business to the surreal, meandering path of Alzheimer's.

It is time to help Billie negotiate her way down the hill.

CHAPTER TWO

Seizures

“This is ridiculous.”

— Billie

On day fourteen of my caregiving career, Frank calls at seven in the morning. “Karen, can you come now? Billie is having a seizure.”

In six minutes, I’m across town in the upstairs bedroom of his 1930s Craftsman-style home.

“Oh, here it comes again,” Billie cries. I sit on the bed next to her. Antique springs creak as she leans over the side of the carved walnut bed and vomits into a wastebasket.

Billie wraps her arms around her stomach and winces. Her cycle of pain, perspiration, vomit and expelled mucus ends in a deep sleep.

SEIZURES

I push sweaty gray hair away from her closed eyes. “What happened?” I ask.

Frank shifts his weight from left foot to right. He strokes his beard, then fidgets with his eyeglasses.

“I may have given Billie an extra dose of medicine.” He stares at me with worried brown eyes. “It’s possible I gave her two pills last night.”

Donepezil hydrochloride is a drug prescribed to relieve anxiety and paranoia caused by Alzheimer’s. Billie’s dosage is one pill before bed.

Downstairs a wooden screen door slams. A familiar voice calls, “Hello? Anyone here?” Frank descends to tell Betsy, a family friend, what’s happening. I hear them chant their morning Buddhist prayers a few minutes later.

In the next hour, Billie suffers three painful cycles. Her face is as white as the washcloth I use to wipe her steamy forehead. Perspiration saturates her pink flannel nightgown. The wet bed sheet clings like a magnet to the plastic mattress cover.

“Lie on your side Billie. I’ll rub your back.”

“Ohh-kay,” she moans.

Soon, she falls asleep. As I rise to rinse the washcloth in the adjacent bathroom, Billie’s body jerks. Her right arm jumps from her side and hits the bed stand. A glass of water crashes to the hardwood floor. Billie’s head snaps back. Her body stiffens. Her green eyes roll until her sockets are white.

“Oh God! Billie!”

I shake her shoulders.

“BILLIE!”

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No response.

"Call 9-1-1," I scream. "Call 9-1-1."

Frank and Betsy appear. Betsy is on the cordless phone with a 9-1-1 dispatcher. Questions and answers fly across the room. Betsy disconnects. "They're coming."

I shake Billie. "Billie, wake up Billie."

Faint sirens.

Loud sirens.

Betsy races down the stairs to meet the paramedics. Billie stirs. She groans and opens her eyes.

Two paramedics and a fireman stomp up the stairs. Metal cases filled with medical paraphernalia crash to the floor. The room is crowded. The sloped ceiling feels claustrophobic. Billie looks like a worn-out rag doll tossed on the bed.

A thirty-ish EMS worker shines a penlight at Billie's tiny pupils. "Hi. I'm Liz, a paramedic. Can you tell me what you're feeling?"

"I don't know." Billie looks at each stranger's face.

"She has Alzheimer's," I say.

Liz adjusts her blond ponytail. She grabs Billie's chin with her thumb and two fingers, then leans forward. "Do you hurt?" she shouts.

"I don't know." Billie wiggles her chin free.

I say, "She clutches her stomach and groans, then she vomits. And, she's burning up."

Liz talks into a radio attached to her shoulder. "We'll take her to emergency so they can examine her."

Liz and her partner Dave lift Billie's plump, pear-shaped body into a transport chair. Before the seat belt is buckled,

SEIZURES

Billie seizes again. Dark-haired, muscular Dave catches Billie before she falls. He lays her stiff body on the bed. Liz monitors vital signs.

In ten seconds, Billie regains consciousness. Dave and Liz secure her in the transport chair and carry her downstairs to the ambulance. They drive six blocks to St. Anthony's Hospital.

Four and a half hours later, in a chilly emergency room cubicle, Billie sits on the edge of the bed dressed in a hospital gown and gray slipper socks. Her hair, recently cut short for easy care, sticks out in all directions. She is one of six patients in the ER.

The beds form a semi-circle around the nurses' desk. Each cubicle contains a wall of medical instruments. Blue nylon drapes swing around the beds like a shower curtain for visual privacy. There is no sound barrier.

Other patients, in assorted stages of emergency, each have a friend or family member with them. Everyone whispers a collective "there, there, everything will be okay."

Our nurse whips the blue curtain aside. In a sharp voice she reports, "Nothing is wrong with Billie. She seems fine now. She can go home. Doctor signed off on it."

"Really?" I look from the nurse to Billie. "Well. Okay Billie, let's get your clothes on."

The nurse vanishes without closing the curtain.

Billie leans against the bed as I pull on her pants. Before her foot is in the second leg, she seizes for the fourth time today. Her five-foot-three-inch frame stiffens. She falls sideways.

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“Nurse!” I catch Billie’s falling body. “NURSE!”
The nurse appears, and together we lay Billie lengthwise on the bed.

Fifteen seconds later, her eyelids flutter open.

“She’s not going anywhere,” the nurse barks. “I’ll call the neurologist to come look at her.” She pulls the sheet to Billie’s waist then rushes away.

I sit on the bed next to Billie. We hold hands and wait.

“Frank’s waiting for us to come outside,” I say.

“Why are we here?” Billie asks.

“You fainted and the doctors want to make sure you’re okay.” We repeat the conversation seven times before the neurologist arrives.

“Hi, I’m Doctor Lin.” She glances at her clipboard. “Are you Billie?”

“Yes.” Billie smiles.

Dr. Lin taps her pen on the clipboard. “I’m going to ask you a few questions, Billie. I want you to remember this green pen for me, okay?”

“Sure.” Billie swishes her legs back and forth under the sheet.

“Do you know where you are?”

“Right here.”

“Do you know who is with you?”

Billie grimaces.

“Who is the president?”

“Oh, that guy,” she laughs.

“Do you remember what color my pen is?” Dr. Lin taps Billie’s arm with the green ballpoint.

SEIZURES

“Sure. What now?”

Dr. Lin orders an MRI, carotid artery ultrasound and a CAT scan. Then she tells us, “Today is Saturday. These tests aren’t performed on the weekend, so Billie will be admitted and have the tests on Monday.”

Hours later, in a pink room with a floral wallpaper border, the mood grows tense. The cozy mauve visitor chairs don’t fool Billie. The industrial linoleum floor, hospital bed and blue privacy curtain trigger her internal alarms.

“This isn’t home,” Billie says, “Why am I here?”

“Because you fainted.” I stroke her arm. “The doctors want to make sure you’re okay.”

“Why can’t I go home? I have a nice home. This is ridiculous!”

“You fainted and the doctors want to run tests.”

Billie throws back her bed covers. “I have to go to the bathroom.”

“There’s a catheter hooked to you.” I tuck the blanket under her hips. “You don’t need to get up.”

“Why are we here?” Billie pounds her fists on the bed.

“We’re waiting for the doctor.”

She kicks her feet under the sheet. “Why can’t I go home? THIS IS RIDICULOUS!”

A skittish, pregnant nurse darts into the room. She lisps, “Bil-wie, can I take your tem-pa-ture? We need to do this. Open your mouth.”

Billie bops her in the nose. A few minutes later, Billie punches another nurse in the arm as she delivers a dinner tray. Two strikes and Billie is in arm restraints.

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She scrunches her face. “#%*@ this!” She struggles to free her arms. “Can’t you get me out of this?” she asks.

“I don’t know how,” I say.

“That’s stupid.” Her mouth twists with rage. “You’re stupid. Stupid!” She curses again and again, and again.

“Don’t get upset Billie,” I say.

“Why not?” she hisses, “You’re upset!”

Ten silent minutes later, Billie forgets. She makes funny faces at the nurses’ backs. We discuss things and people we like.

Patrice, the pregnant nurse, returns at eight with Billie’s bedtime sedative. “Oh-Oh-kay Bil-wie,” she stammers. “Here’s sum-thing for you to eat.” She positions a tiny white pill on Billie’s tongue.

Billie spits the pill onto the bed.

“Oh. No, no, no, Bil-wie. You need to SWALLOW it.” Patrice pretends to put the pill in her mouth and swallow. “Like this,” she says, “Mmmm.”

“Come on, Billie,” I say, “You’ll feel better.”

Billie sticks out her tongue at me. Patrice drops the pill onto it. Billie chomps it. She chews until it’s gone. Soon, she is her sweet, gentle self.

“This is a nice place,” she says. “Is it your house? Did Charlie fix it up?”

“Yes he did, do you like it?” I ask.

“He did a beautiful job.” Billie looks at the floor to my right and smiles. “How sweet. Whose dogs are those?”

“Those are our dogs.” I smile at the imaginary animals.

“Pretty.” Billie’s eyelids flutter, droop and close.

SEIZURES

More sedatives make Billie's three tests possible on Monday. She remains groggy that night, but the nurses don't remove her restraints.

On Tuesday morning, the doctor delivers the test results. "Billie is healthy except for the Alzheimer's. There is no reason for her seizures. We don't know what caused them."

Billie is right. This is ridiculous.

CHAPTER THREE

Watch Your Step

“It’s easy to see things once you know where you are.”

— Billie

Outside, Billie scurries past the kitchen window, across the side yard and into the alley.

I wonder aloud, “How does a seventy-two-year-old woman bent in half, walk so fast?” My knife clatters into the ceramic sink as I drop lunch preparations to chase her.

Alzheimer’s fogs Billie’s mind. Sedatives she received during her recent three-day hospital stay make her body bend at a right angle. It’s not a good combination.

According to Billie’s doctor, sedatives often have a “second life” or residual effect. In older people the symptoms can last days after dosing ends.

WATCH YOUR STEP

“Normal posture will return,” the doctor assures me, “when the meds are completely out of her system.”

Until Billie is five-foot-three again, I must make sure she doesn't topple forward.

When I reach the alley, Billie is four blocks ahead, turning right onto Fifteenth Avenue. I race down the alley and find her just past the corner. She stands in the street facing the curb. Her nose is inches above the ground. She scratches her neck and stares at the granite street edging.

“Hey Billie, whatcha doing?” I ask.

She points to the steep incline of lush manicured lawn above the curb. “I want to get there,” she says.

“Let's go over here.” I wave at the adjacent driveway with an easier grade.

“No, no. I can do it. But...”

“Then let me help you.” I put an arm around her shoulders.

Billie aims her index finger at a giant pile of dog dirt in the grass in front of us. “Watch your step,” she warns.

I smell it before I see it. “Okay. Let's try the driveway instead.”

“Oh no, no.” Billie shakes her head. She draws a deep breath. “One, two, three, let's go.”

Pushing me for momentum, she puts her right foot on the curb. Her second step reaches the grass. When her right leg swings forward again, Billie doesn't notice her foot lands on the mound. She bends closer to the ground and speeds her gait.

“Whoa, don't go so fast.” I grab her arm. “You'll fall if you don't slow down.”

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“Okay,” she sighs. She strolls for thirty seconds, then races again.

At the corner, I suggest the shortest route home.

“No.” Billie freezes in place. “We have to go this way.”

I look at her determined face. An argument makes as little sense as taking the long way home. When she yanks my arm, I cooperate. We retrace our steps until we’re back in the alley.

Sweat dances across Billie’s forehead. On this seventy-five degree day she wears two tee shirts, a green cotton pullover, and my father-in-law’s gray wool cardigan which hangs to her knees. All this is over a pair of black pants. Layered clothing is another symptom of Alzheimer’s. Billie’s brain can no longer determine appropriate dress. She forgets she has a shirt on and adds a second and often a third one.

I coax her out of the wool cardigan when we pause to rest. We walk four more feet before she wants to remove her oversized pullover. “Too hot.”

Billie wipes her brow with the sleeve, then disappears inside her sweater. A muffled “uh-oh” reaches my ears. I plant my feet in the gravel. It’s a struggle to keep Billie upright. Her head pushes into one sleeve, pauses, then enters the other sleeve. She’s stuck.

“Oh God,” I mutter. Our feet kick loose stones around the alley. Twice, we shuffle in a full circle. My left arm hugs Billie’s waist as I pull the sweater loose with my right hand. A warm waft of her perspiration fills my nose as she appears outside her sweater.

“There you are,” I say.

Billie squints at the sun. “Here,” she tosses the pullover at my face, “that’s better.”

WATCH YOUR STEP

“Thanks a lot.” I pull her arm like a lever to straighten her. A quick glance up and down the alley reveals no witnesses to our antics. We resume our journey.

Slow. Race. Repeat.

Slow. Race. Repeat.

A block from home I ask, “Billie, why are you walking so fast?”

She stops to look up at me from her hunched position. “I’m so tired,” she pants, “I want to get home quick so I can take a nap.”

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