

# ALZHEIMER'S STORIES

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.

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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,

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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

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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

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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.