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Ed and Rebecca: A Love Story

IT WAS A BEAUTIFUL North Carolina morning in August 2013. Rebecca and I (Ed) were sipping our coffee on the back porch, part of our morning ritual. Without warning, the awful moment I had long dreaded finally arrived. Rebecca looked at me and said, “I have no idea who you are.” Her blank stare confirmed that she really meant it.

“But Sweetie, I am your husband, Ed. You are my wife. We’ve been married for 33 years.” This clue, more like a plea, didn’t help. The pain of the moment drove me from the porch into the house. Tears streaming down my face, I stood before our family portrait, taken only months before, at Thanksgiving. I looked into the faces of our daughter, Erin, her husband, Darian, their two-year-old son, Paul, our other daughters, Leah and Carrie, sweet Rebecca, and me. I was overcome with the need to talk to one of the girls. I reached Leah first. When she answered, there were no words, just sobs, deep sobs that started in my feet and shook my body as they reached for my heart, landing in my eyes, which streamed like a leaky faucet.

“Mama has forgotten us. We’re gone.”

Many times I’ve reflected back on that terrible morning, asking myself the same unanswerable question: how could 37 years

of a loving relationship and a third of a century of marriage disappear from Rebecca's mind overnight?

Rebecca Lynn Easterly and I began dating in the fall of 1976. We were students at the University of Iowa, where we both were sophomores, she a speech pathology major, I, premed. I asked her out on my 19th birthday, October 30th. She was sitting in the student union studying over a cup of coffee, and she was beautiful. Silky-smooth blonde hair, long legs, a blue leotard top, bellbottom jeans, and a face that radiated kindness. We had met briefly the year before. I hoped she'd remember me. After getting up the nerve to reintroduce myself, she accepted my invitation for our first date. One week later we went dancing and had dinner at the Brown Bottle, an iconic Iowa City restaurant. During dinner and afterwards, we talked and talked and talked. We had so much in common. Although we both had alcoholic fathers, we shared a love of family, especially children, and an appreciation for nature

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as a reflection of the Creator's hand (though at the time, I was a committed agnostic). I walked her home, we shared our first kiss, and we both knew that we were in love. Three weeks later, we talked about marriage and the desire to have three children, all daughters. Three and a half years later, we were married.

Rebecca graduated summa cum laude with a near-4.0 GPA, in the top 1 percent of her graduating class. She later received a master's degree in speech pathology from Iowa. After completing

my premed studies, I went to medical school at Rush Medical College in Chicago. In May 1983, we headed north to the Mayo Clinic in Rochester, Minnesota, three-week-old Erin in tow. There, I completed my internship and residency in radiation oncology and remained as an attending physician, launching a career as a brain tumor doctor. Our second daughter, Leah, was born in 1985, and three years later Carrie completed the trio of daughters we had dreamed of during our courtship. We spent 12 years in Rochester, happy and surrounded by family and friends.

In 1995, we headed southeast to Winston-Salem, North Carolina and the Wake Forest School of Medicine for an offer too good to refuse: a radiation oncology chairmanship and the opportunity to establish a research program in how brain cancer and its treatments affect brain **cognitive function** (words in bold type are defined at the end of the chapter). We thrived as Southerners. Erin, Leah, and Carrie marched through the ranks of elementary, middle, and high school, and then college. Throughout those years, Rebecca was “supermom.” Navigating with her Day Planner notebook, kindness, and grace, she organized, fed, and nurtured our family while I was busy seeing patients, publishing journal articles, teaching, and getting research grants.

In the spring of 2005, as our family was preparing with excitement for Erin and Darian’s wedding, Erin noticed something odd: her “super mom” was struggling to keep up with the details of wedding planning. It all came together, though, and in May we celebrated the marriage of our oldest daughter. One year later, we mourned when Rebecca’s older sister, Leslie, died from colon cancer. This was the first tragedy our extended family had experienced. Rebecca was deeply saddened by Leslie’s death, as she and Leslie had been kindred spirits. Throughout the summer, fall, and

winter of 2006 and the spring of 2007, Rebecca was sad. She was distant, a bit disorganized, and forgetful. I attributed it to grief and a gradually emptying nest, until one Saturday morning as we sat, me reading the newspaper, Rebecca the latest issue of *U.S. News and World Report*. Rebecca said, "I've read this article three times and I can't remember a thing about what it says." At her age, 53, I knew this was not normal.

One day the following week, my car was in the shop. Rebecca was going to pick me up from work at 5:30 p.m. and take me to the dealership to retrieve my car. Usually prompt, she hadn't arrived on time. At 6:00, I called her, a bit miffed. "Are you going to pick me up?" She had no idea she was supposed to come and get me.

"Okay, I'm on my way," she said.

We lived only 10 minutes from the medical center, but she didn't arrive until 6:30.

"What took so long?" I inquired.

"Oh, I took a different way of getting here."

When she described her route, I realized that she'd gotten lost along the way. I had always marveled at Rebecca's sense of direction, and had even nicknamed her "the human compass." Now I was really worried.

Wake Forest School of Medicine is well known for both geriatric research and care. In mid-2007, I made an appointment for Rebecca to see Dr. Jeff Williamson, head of geriatrics and a well-known **dementia** expert. In his initial assessment, Dr. Williamson diagnosed Rebecca with depression and prescribed an antidepressant.

"Let's see if things improve after a couple of months on the medication. Depression is a common cause of memory loss." But

I could tell he was worried that something more was going on. So was I.

After her symptoms failed to improve, Dr. Williamson decided to order some blood tests, a magnetic resonance imaging (MRI) scan of Rebecca's brain, and assess some of her **cognitive functions** such as attention, memory, language, multitasking, and spatial skills. The blood tests came back normal, but the MRI showed mild shrinkage of Rebecca's brain, especially in the regions that control memory and spatial skills. The cognitive assessment confirmed loss of short-term memory and spatial skills way out of proportion with what would be expected for Rebecca's age and educational level.

Dr. Williamson told us, "My diagnosis is something called **mild cognitive impairment (MCI)**, a condition that often leads to Alzheimer's disease. I think you should get a second opinion. Rebecca is too young to have Alzheimer's, especially since she doesn't have any family history of the disease."

Our next-door neighbor in Rochester, Minnesota had been a Mayo Clinic neurologist named Ronald Petersen. He and his wife, Diane, had two children who were about the same ages as our girls. Diane and Rebecca often carpooled, as our kids went to the same elementary school. Affectionately known to us as "RP," Dr. Petersen was a nationally and internationally recognized expert on Alzheimer's disease. In fact, it was his research that led to the discovery of MCI as a precursor to Alzheimer's. Getting a second opinion from him seemed logical. Not only was he "the best" dementia doctor in the world, he had known Rebecca for 20 years.

In the early summer of 2008, we spent a week at the Mayo Clinic where Rebecca had an extensive evaluation to find the cause

of her memory loss. In addition to blood tests, a spinal tap, and more in-depth neuropsychological testing, Dr. Peterson ordered a special MRI scan and two Positron Emission Tomography (PET) scans. One PET scan was done to reveal Rebecca's brain metabolism; the other, a newer type of PET scan, was done to reveal amyloid, a protein that collects abnormally in the brain, causing inflammation, deterioration, and shrinkage. Amyloid and another protein, tau, form the "plaques and tangles" that are thought to cause the brain damage of Alzheimer's disease.

Despite our earnest hopes and fervent prayers to the contrary, the diagnosis was definitive: **early-onset Alzheimer's disease**. The prognosis: 8–10 years' life expectancy, progressive decline in all brain functions, the need for professional caregivers, and possibly nursing home placement.

We embraced as
we cried, speaking our
love for one another
in silence.

After receiving the news, Rebecca and I drove in silence to the Minneapolis airport to catch our return flight home. We wept as we drove, exchanging glances filled with sadness, fear, and uncertainty. At Pine Island, a small town north of Rochester where Re-

becca had worked as an elementary school speech teacher, I pulled over. We had to talk. Rebecca asked me, "What does this mean for us? For the girls?" She had already forgotten what Dr. Petersen said, so I told her again. We then embraced as we cried, speaking our love for one another in silence, reaffirming the vows we had made to each other 28 years earlier.

Her voice full of sadness, Rebecca said, "I don't want to be a

burden. I want Erin, Leah, and Carrie to live their lives, pursue their dreams and not let this get in the way. I will be okay. I know God loves me and will take care of me. Eternity in heaven is as real to me as life on this earth.” This was the only time we would ever directly speak about her Alzheimer’s.

In the years that followed, Rebecca’s dementia progressed relentlessly through the stages of Alzheimer’s disease. By the spring of 2010, her driving skills had deteriorated to the point that she was no longer safe on the road in her bright red Volkswagen Beetle. Navigating from home even to nearby destinations had become too challenging. On one occasion, a wrong turn took her several towns south of Winston-Salem, about 25 miles from home. Scratches mysteriously appeared on the side of the car. She drove very slowly, stopping in the middle of the road when she was unsure of where to go. Finally, the keys had to be taken away.

“I don’t understand why I can’t drive,” she protested. “I’ve never gotten a ticket nor have I been in an accident. It’s unfair.” Like so many people who have dementia, she didn’t have insight into how the disease was slowly stealing her abilities, moving her toward disability.

Shortly after Rebecca had to give up her car keys, she and I took a driving trip to the Pocono Mountains. We made a stop at the Crayola factory, which brought back warm memories of Rebecca and our daughters coloring around the kitchen table when they were younger. What we had hoped would be a fun adventure turned sour when Rebecca left her purse under a bench while we watched a demonstration on how crayons are made. Unfortunately, we didn’t realize that the purse was missing until after the Crayola factory had closed. We spent the night nearby and went back in the morning, but the purse was nowhere to

be found. We filed a police report and left. This incident upset Rebecca immensely.

“I hate my brain,” she said, teary-eyed, as we drove away.

Later that summer, while walking to the grocery store, Rebecca got lost. As she was about to turn onto one of the busiest north-south streets in the city, Elizabeth, a family friend, just happened to be driving by and saw Rebecca looking at street signs. It was obvious that Rebecca was trying to figure out where she was. Elizabeth pulled over, lowered her window, and called to Rebecca, “Where are you headed?”

“To the grocery store,” Rebecca replied.

“Jump in. I’ll give you a ride,” Elizabeth offered, realizing that Rebecca was walking in the opposite direction of the store.

To this day, our family thinks of Elizabeth as a guardian angel, and we wonder what might have happened if she hadn’t been in that place at that time.

Shortly after the grocery store incident, we hired Rebecca’s first paid caregiver. Erica, a certified nursing assistant (CNA), spent the weekdays companioning Rebecca on her journey with Alzheimer’s disease. Within four years, Rebecca would require round-the-clock caregivers. This crew—affectionately known as the “A-team” (because their names, Letisa, Fatima, Tasha, and Florina all end in “a,” as does Rebecca)—is still with us, caring for Rebecca day and night.

Looking back, I would have to say that the most difficult and challenging days of Rebecca’s Alzheimer’s journey were the four months that followed the awful day in 2013 when she “lost” the girls and me. She became very agitated, especially starting at dusk and on into the early evening (known as “**sundowning**”).

“I want to go home,” she’d say, marching around the house

from door to door, trying to escape.

“But you are home, Sweetie,” I would tell her. “This is our home.”

She could not be comforted. Rebecca was yearning for her childhood home, a small bungalow in her hometown of Cedar Rapids, Iowa, where she had lived in the mid-to-late 1960s. I would have to physically block her attempts to exit as she punched and kicked at me, behaviors that were so atypical for sweet and gentle Rebecca. Dr. Williamson prescribed a medication that reduced some of Rebecca’s aggression, but caused her to become withdrawn and deeply depressed. During this time she would lie on her bed or the couch and sob inconsolably. Dr. Williamson then tried a different medication which, over time, reduced her agitation and returned her mood to normal and helped her sleep.

After Rebecca no longer recognized me as her husband, we continued to sleep in the same bed, but she turned her back to me and stayed on the very edge of the bed, as far away as she could be without falling out. One night she became very agitated and told me she didn’t want me sleeping in the same bed as her, so I set up a twin daybed in the corner of our bedroom. Those first few nights I was sleepless, grieving. We were only separated by a few feet, but it felt as though she were a million miles away.

Early in our marriage, Rebecca and I discovered we both fell asleep more easily if we were touching one another, either by “spooning,” facing in the same direction with my one arm wrapped around her, or turning opposite of one another, “rump to rump.” Sometimes we wouldn’t go right off to sleep. Rather, we’d make love, then spend some time together in one another’s arms, talking about how blessed we were to have each other and to have Erin, Leah, and Carrie. For the first couple of months of

being alone at night in the twin bed, I would lie awake, literally aching with the desire to touch Rebecca, to lie in bed with her, to hold her. During these months I had several long conversations with God, thanking Him for bringing Rebecca and me together as husband and wife, for blessing us with amazing children, but in the same breath asking how I could love this woman without being able to touch her. With this loss I began my own journey of loneliness and celibacy.

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In early 2014, I moved into my own bedroom since Rebecca was getting up multiple times during the night and I found it impossible to get enough sleep to function at work. She had no concept of the day, date, month, season, or year. She was unable to read

or write, even to sign her own name, or add two plus two. Another challenge was spatial orientation. She had lost the ability to center her bottom over a chair or couch and required assistance just to sit, including sitting on the toilet. With these further declines, evening and nighttime caregivers were added to the A-team. This meant that Rebecca and I would never again have an evening alone at home together. There didn't seem to be any part of our lives that Alzheimer's disease hadn't taken away or changed.

In the two years since then, Rebecca has transitioned into late-stage Alzheimer's disease. She lives only in the moment with no remembrance of the past and no thought of the future. Her days are spent coloring at the kitchen table, putting simple puzzles together, and breaking twigs into small pieces. She initiates no

conversation, speaks unintelligibly, and often needs to hear something repeated multiple times before she can understand what has been said to her. She walks slowly and unsteadily, always at risk for a fall. Because she is so unsteady, and also has difficulty processing visual information, someone must accompany and hold onto her at all times. Due to unpredictable urinary incontinence, she wears pull-up adult diapers. She needs help using the toilet, taking a shower, and getting dressed. Her medicines must be crushed and mixed into food as she cannot swallow pills any longer. Despite all this, she is happy most of the time.

Though she doesn't acknowledge me as her husband, at some level I am familiar to her. At the very least, I'm the nice man who lives in the same house that she does. My love for her is unaltered. When I return home from work, my time is Rebecca's time. It is important to me that I make her supper and help her eat. The smile on her face when she is given her dessert—always ice cream in a cone or a dish—brings as much joy to me as it does to her. Afterward, we sit on the couch and watch old musicals on a DVD player. Her favorite is *The Sound of Music*, which we've watched together hundreds of times. For Rebecca, the familiarity of each song is comforting. For me, it is a time when we're physically close, perhaps holding hands, being present to one another. Bedtime is also a special time. After her caregivers prepare her for sleep and get her tucked in, I will spend five or ten minutes saying goodnight, our only alone time each day. She will let me kiss her on the cheek or forehead. I tell her, "I love you. I love you more than anyone else in the whole world. You are the best sweetie a man could have. And we're married. We've been married for 35 years. We have three daughters, Erin, Leah, and Carrie. They love you and know they have the best mommy ever. See you in the

morning. Sleep tight and don't let the bedbugs bite" (something we always said to the girls). Sometimes, Rebecca will say thank you. Once in a while, she'll utter something that sounds like "I love you too." Most often, her eyes are closed and she is drifting off to sleep.

The Christmas 2015 season was a time when our entire family was together. We connected with Rebecca, loving her in as many ways as we could, and loved she was. Erin shared a good-morning hug and sat with Rebecca drinking her morning coffee, just as she had since high school. Leah played familiar songs on her guitar while she and Rebecca "sang" together. Carrie snuggled next to Rebecca on the couch, her head on Rebecca's shoulder. My favorite way to add to the fun was sneaking in some kisses on Rebecca's cheek and neck, which often made her giggle like a schoolgirl and say "yuck" as she wiped off the side of her face. Rebecca's mom visited with freshly baked cookies; her friends brought flowers; and her sister and sister-in-law came for a visit just to spend time with Rebecca. Her caregivers had their own ways of showing love: they brushed her hair, painted her nails, and brought her the gift of a beautiful new blouse. Even our grandson, Paul, was drawn to his grandmother, helping her put a simple puzzle together or sharing a marker and coloring on the same page with her. We chose, with intention, to experience the joy of Rebecca's presence, rather than dwelling on the possibility that this very well might be our last Christmas together as a complete family.

Rebecca is now in her ninth year on the Alzheimer's journey, and I don't know how much longer the journey will last. It has been a long, hard journey, emotionally, physically, and spiritually, and one that I wish we were not taking. Yet there are so many things I've learned, about Rebecca, about me, and about us, be-

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cause of it. I know, if the situation had been reversed, me with dementia and Rebecca as my care partner, she would have taken care of me with the same level of commitment that I've had in caring for her. I also know that if I could somehow carry this burden for her, trade her diseased brain for my normal one, I'd do it without a second thought, just to know that she would be able to live to a ripe old age knowing those she's loved. If I had known before we married that she was going to develop early-onset Alzheimer's, I still would have married her in a heartbeat. The life we've had—now 40 years together, 36 of them married, three children, a son-in-law, and two grandsons—has been more than we could have ever dreamed. And I have learned, through the grace of God, to find an endless supply of love for Rebecca and to maintain emotional intimacy with her. I know that at some level, in her own way, she also loves me. And while the thought of losing her is unbearable to all who love her, we are comforted by the knowledge of her deep personal faith and the way she has lived her life because of it.

EDWARD G. SHAW
Winston-Salem, NC

Terms to Know

The bolded words that appear in Ed's story are defined and explained below, along with other terms and facts about Alzheimer's disease (AD). Understanding these key terms and facts will help you gain the most from the remaining chapters of this book.

Care Partner. The care partner is the primary person providing direct care to the person with dementia, most often a spouse or an adult child. In the United States, Canada, and China, most dementia-related resources and literature refer to this person as the *caregiver*. In some other countries, *carer* or *caretaker* is preferred. At the risk of bucking convention, throughout this book we have mainly used the term *care partner*. We prefer this term, especially in the early stages of AD, because it is less hierarchical, allowing the person with the disease to feel emotionally equal to the person providing care. Our observation is that family care partners tend to provide care with a sense of loyalty that aligns with the definition of *partner*: “a player on the same side or team as another” (dictionary.com). Thus, we are more comfortable applying the word *caregiver* to paid professionals than to family members. At the same time, we acknowledge that around the midpoint of the disease, care partnering transitions to a more truly care *giving* role.

Cognitive Function. The brain has five cognitive functions:

- Attention
- Memory and learning
- Language
- Executive (the ability to plan, solve problems, make decisions, and multitask)

- Visual-spatial (The *visual* aspect allows us to recognize faces; the *spatial* aspect is our internal “GPS”—the ability to perceive relationships between objects in our visual field.)

Alzheimer’s disease is characterized by progressive difficulties in memory and learning, executive function, and visual-spatial function. By late-stage AD, however, all of the cognitive functions are affected.

Dementia. Dementia is not a specific disease, but rather an umbrella term for a wide range of symptoms related to memory loss, declining cognitive function, or changes in personality. There are many types of dementia. Alzheimer’s disease is the most common type, accounting for 60–80 percent of all cases. Because most dementia is due to AD, it gets the most attention from both the media and the medical profession. Thanks to Lisa Genova’s bestselling book, *Still Alice*, the award-winning movie by the same name, a plethora of TV pharmaceutical ads, and high-profile patients, such as President Ronald Reagan and singer Glen Campbell, almost everyone has now heard of Alzheimer’s disease. For this reason, we have chosen to focus primarily on AD in this book. In the chapters ahead, the terms *Alzheimer’s disease*, *AD*, and *dementia* are used interchangeably.

Early-onset Alzheimer’s disease. The majority of individuals diagnosed with AD are 65 years of age or older (late-onset AD). Early-onset Alzheimer’s disease, also called younger-onset Alzheimer’s disease, starts before age 65, often affecting those in their 40s and 50s. Early-onset AD is uncommon, affecting only about 5 percent of those with AD (about 200,000 people in the United States).¹

Mild cognitive impairment (MCI). MCI is the “gray area” between normal age-related memory loss and the memory loss of mild Alzheimer’s disease. A person with MCI has more memory problems than others of their same age and educational level. They may find it hard to remember names, and may forget appointments or social events. They may have difficulty following the thread of a conversation, book, or movie. Decision-making or tasks that require planning may feel overwhelming. Subtle changes in the person’s personality may be present. However, these problems are usually not serious enough to interfere with daily life. While MCI progresses to AD or another type of dementia about 70 percent of the time, some people never get worse, and a few will even eventually get better.

Plaques and Tangles. In 1906, Dr. Alois Alzheimer discovered two abnormal structures in the brains of people who had died of what we now know as Alzheimer’s disease. Today, these abnormal structures are called “plaques and tangles.” Plaques are deposits of beta-amyloid protein (or “amyloid”). Neurofibrillary tangles are twisted fibers of another protein, tau (rhymes with “now”). Amyloid plaques build up in the spaces *between* the brain’s nerve cells (neurons); tau tangles build up *within* the neurons themselves. Most of us develop some plaques and tangles as we age; this is normal. People with AD, however, develop excessive amounts of these proteins, which hinder cell-to-cell communication and cause brain inflammation. Eventually, the toxic presence of plaques and tangles causes so much damage that nerve cells die. As plaques and tangles spread throughout the brain, widespread cell death occurs. As neurons die, the brain shrinks, resulting in memory and cognitive function loss, personality changes, and the progressive inability

to carry out normal daily functions. The exact role of plaques and tangles is not clearly understood, but scientists do now know that amyloid may begin accumulating in the brain 10 to 20 years before the first symptom of forgetfulness appears.

PWD. Person with dementia. (You will see this abbreviation throughout the book.)

Sundowning. Sundowning is a state of confusion that typically begins at dusk and extends into the evening hours. Challenging behaviors may include agitation, aggression, anxiety, fear, pacing, and wandering. Some individuals express a yearning to “go home” to a time and place in the past, perhaps from childhood. The cause of sundowning is unknown. About 18 percent of those with AD experience sundowning.²

FACTS ABOUT ALZHEIMER'S DISEASE

- As of 2016, 5.4 million Americans have AD.
- One in nine Americans age 65 or older has AD. One-third of those age 85 and older have it.
- Older African Americans are twice as likely to get AD as older whites.
- Older Hispanics are about one and a half times as likely as older whites to get AD.
- Nearly two-thirds of those with AD are women.
- Age is the greatest risk factor for AD.
- Two-thirds of all dementia caregivers are women. Over half are adult children caring for parents.

- About 250,000 children between ages 8 and 18 help someone care for a person with AD or another dementia.
- At present, there is no way to prevent, cure, or slow the progression of Alzheimer's disease.

Source: Alzheimer's Association, *2016 Alzheimer's Disease Facts and Figures*³