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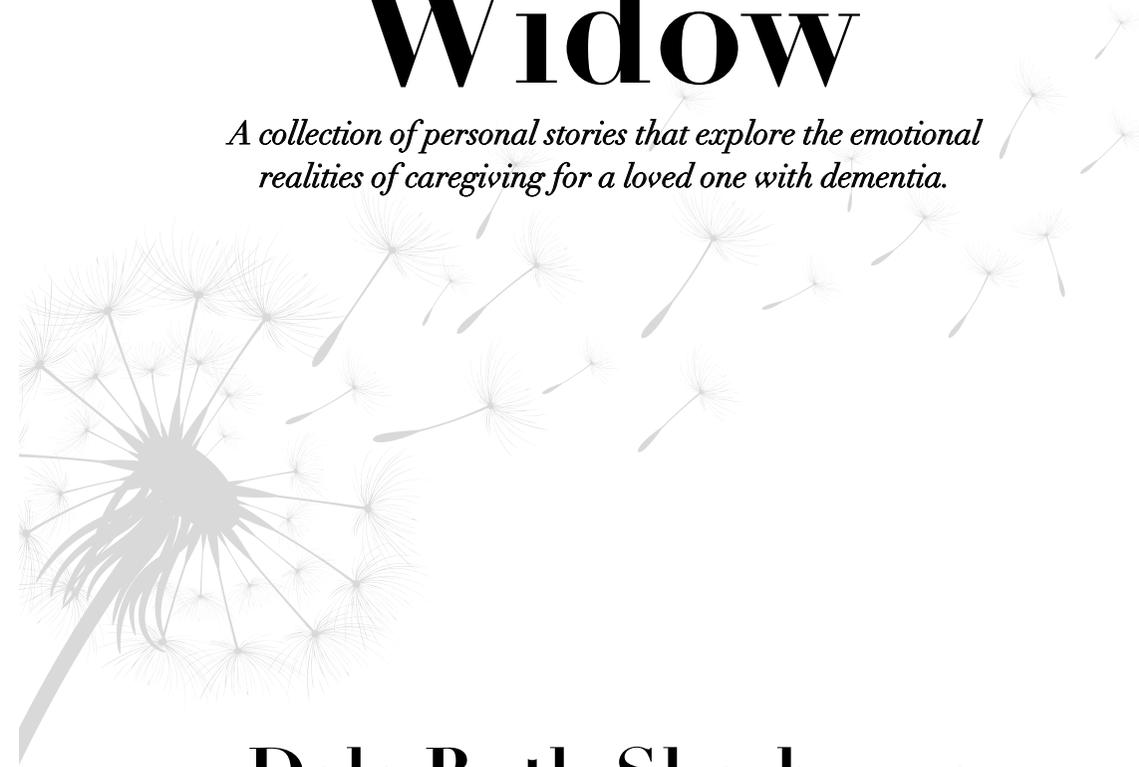
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Neither Wife nor Widow

A collection of personal stories that explore the emotional realities of caregiving for a loved one with dementia.



Dale Ruth Sherburne

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*There are only four kinds of people in the world—
those who have been caregivers,
those who are caregivers,
those who will be caregivers, and
those who will need caregivers.*

~Rosalynn Carter

Neither Wife nor Widow

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The terms “Alzheimer’s disease” and “dementia” are used interchangeably for purposes of this book. It is acknowledged Alzheimer’s disease cannot be definitively diagnosed until examination of the brain upon death.

Data referenced in this book is consistent with the author’s diligent research and conclusions from the reference materials documented. The author is not liable for the data as presented or its subsequent distribution.

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Caregiver to Caregiver

*The courage it takes to share your story might be the very thing
 someone else needs to open their heart to hope.*

~Unknown

Hello, kindred caregivers...this book is a heart-to-heart conversation between us, just you and me. (But a must-read for everyone.) It’s a chance to talk with you, not at you, about what we do and how we feel as caregivers for our loved ones with dementia.

The Alzheimer’s journey I describe in my family may not match yours, and my caregiver emotions may not reflect your own. But there’s no right, no wrong, in “caregiver-land.” And above all, I believe we share a common sense of grief and loss. I dare say that unless someone has carried this load, it’s almost impossible to grasp the daily horror and disbelief of watching the personhood of our loved one ever so slowly disintegrate before our eyes. It is the cruel, unrelenting march of an interminable, terminal illness.

I, for one, desperately needed to know my confusing jumble of emotions—and yes, even my not-so-pretty thoughts—were an expected and normal byproduct of grueling, never-ending caregiving. I craved release from my guilt. I needed to know I was doing my best even on a bad day. And that no one had the right to judge me. No one.

My sole desire with this book is to help caregivers internalize that we are not alone, neither in our experiences nor in the emotions we feel. They are universal, all. We are survivors, proud of caregiving that could bend the soul but never break it. We are one with the untold numbers of silent, caregiver heroes who willingly give our all to our loved ones, give it again, and still yet again.

Know that you are magnificent! I salute you.

Tribute to Russ

In love, one and one are one.
~Jean-Paul Sartre

This book lovingly honors Russ, my husband, and father to our daughters, Holly and Heidi. Family names are used throughout the book in proud tribute to the intelligent, generous, kind, and funny man that he was. There is no shame, no secrecy, in his having Alzheimer's disease. Anonymity only perpetuates the social taboo associated with dementia.

Russ was a career-long electrical engineer employed by a utility company. Suspicions regarding his behavior arose following his early retirement at age fifty-five. Signs of dementia gradually became more apparent, and Russ was diagnosed with early-onset dementia in his early sixties. He remained at home, active and physically healthy, for another ten years. He entered a nursing facility at age seventy-two and passed away five years later at age seventy-seven, still a physically able man.

Russ was a champ, and like all those living with the devastating effects of Alzheimer's disease, deserving of immense respect. The stories our family uses to describe his journey, and our associated emotions, are honest portrayals of our experience. Please know that Russ's behaviors were solely the manifestation of his disease, *not* of his person. The emotions they evoked in us were not about him, but rather the disease's impact on him and our family. *It is imperative this be acknowledged before reading the pages that follow.* Alzheimer's is a cruel disease and does not paint a pretty picture, but amid the deterioration and heartache are found unexpected moments of great innocence and beauty that can teach us all lessons of life and love.

We love and miss you every day, dear.

Your loving wife, Dale ♥

Our Story

Forever is composed of nows.
~Emily Dickinson

I met Russ at the University of Maine as a freshman, when he was a senior. His kind, unpretentious ways had me smitten from the start, not to mention his intelligence and witty prankster shenanigans. We married while he earned his master's degree in electrical engineering, and I completed my undergraduate degree in child psychology.

We claimed Massachusetts as home for a stint before returning to Maine to raise our two daughters. We lived in a charming 1850s farmhouse with acres of woods, fields, and trails, adding a barn when the passion of both girls turned to horses.

I worked in early childhood special education and later in human resources. Russ's career was in the utility industry, retiring at age fifty-five. Shortly thereafter began his subtle signs of dementia, only to be dismissed by me as early signs of natural aging. By age sixty, however, it was clear something was amiss. I sought help, only to have Russ's gaffes assessed as typical age-related issues, leaving unconsidered the possibility of dementia.

Therein lay the crux of our torturous Alzheimer's journey. An accurate diagnosis was deferred time and again due to reluctance by the medical community to contemplate dementia. Russ's good health and middle age likely influenced this course of thinking and, I confess, only contributed to my relentless questioning whether I was the one with the problem. A journey already wrought with heartache became nearly unbearable.

Russ's Alzheimer's journey lasted twenty years, the last five in dementia care. He passed away at age seventy-seven, his body still strong—the husband and father leaving on his own chosen terms and with “his boots still on.” Yes, a beautiful man, a life well lived.

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Dedications

*There is always, always, always something to be thankful for.
~Unknown*

Immense gratitude to our stalwart supporters who endured with us the rough haul of Russ's illness. I must trust that the many of you know who you are. Our appreciation of your steadfast presence and thoughts can never be adequately conveyed. Your kindnesses will forever be remembered by Holly, Heidi, and me. We thank you from the fullness of our hearts.

To Linda, Russ's soulmate caregiver and my sanity savior, you were the needed miracle that came into our lives. Your uncanny ability to always know what to do for Russ remains a marvel. A thank-you is truly inadequate, but I know you know all that's in my heart.

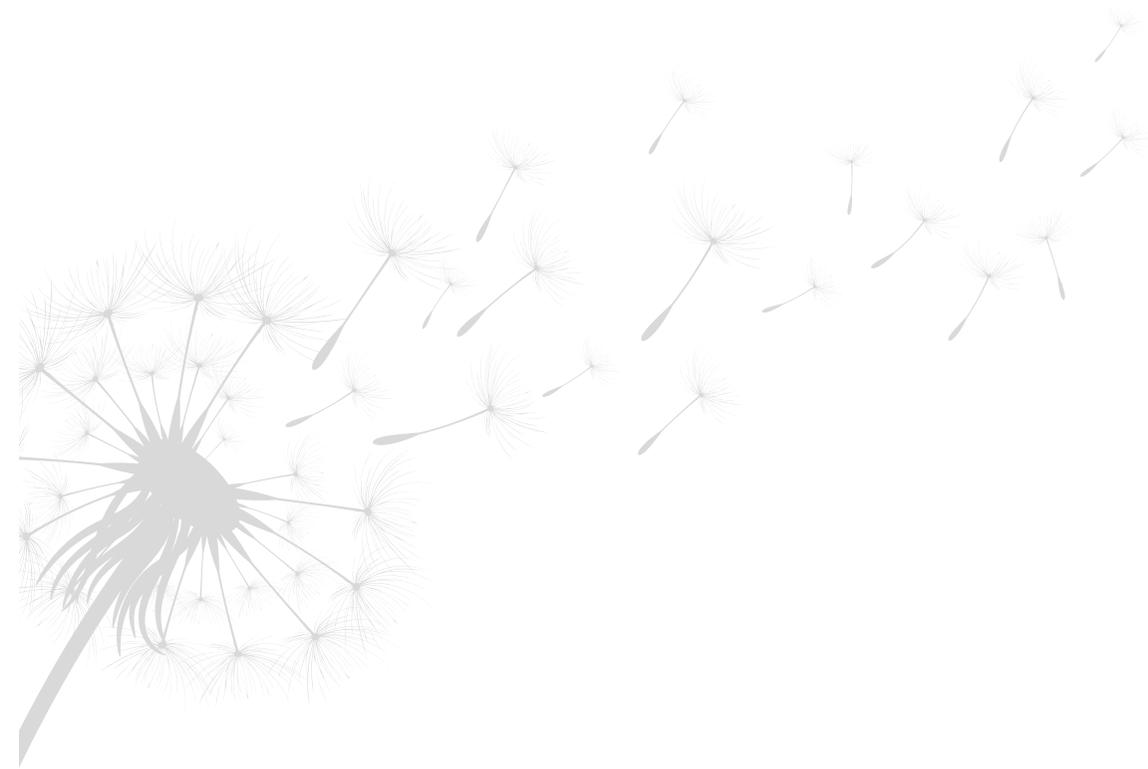
To Russ's sisters and brother who stuck with us every inch of the way, your unwavering support and heartfelt agreement with all our difficult care decisions granted us much needed peace.

To my four-legged furry companions, your unconditional love carried me through the journey. A little fuzz therapy can lift even the lowest spirit. I'm surprised I didn't pat you all bare.

To Holly and Heidi, I'm at a loss on what to say. It's all too big, too much, too deep. Just know I'd never have made it without you. You're the *bestest*. Dad and I will forever love you to pieces.

I. Hmmm

A Six-Year Baffling Journey



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Hmmm

*Wisdom does not come overnight.
~African Proverb*

This was strange. What was happening? Just like that, water slowed to a dribbly trickle from faucets throughout the house. The well couldn't be dry, could it? We'd had plenty of summer rain. Best check things out, pronto.

Uh-oh. The hose at the barn was running full force. Overflowing water gushed from the animals' large water tub, mini ponds forming in the pasture. What on earth was going on?

"Oh," said Russ. "Guess I forgot to turn the hose off." And calmly as that, that was it. Seriously? Was the ever-on-top-of-things Mr. Competent trying to be funny, or was he truly blasé about the mishap? Normally, he'd carry on and fret about sand getting in the pipes, the water pump burning out, and the whole shebang of potential ramifications.

But no. He was completely unfazed by the incident, his reaction one of, "Nah, it doesn't matter." And I, the baffled onlooker, watched with dropped jaw.

Honest emotion: Baffled

Hello

*A little human connection goes a long way.
~Unknown*

The side door was our customary entry into the house, and it passed through Russ's office. His fortunate early retirement at age fifty-five (I was envious) allowed him to be busily parked at his beloved computer when I returned from work. I looked forward to his "Hi" and follow-up chitchat—or not. "Or not" became more common. Well, I could live with that. We'd just catch up later.

But eventually, even his return "Hi" became more infrequent. Sometimes he didn't even turn his head to recognize my presence as I entered after a long day away. What was *that* all about? Yes, he was retired and free to enjoy his hobbies, but I still felt dissed.

This detachment became the norm. I, happily, arrived home. Russ, at desk, zippo acknowledgment. Well, my little buddy boy, this was the day it would stop.

"Russ. I'd appreciate it, when I come home and you're at your desk, that you at least turn around and say "Hi" like you used to. I swear I could be gone a week, and you wouldn't even notice." He looked at me, wide-eyed, confused. "Do you know what I'm talking about?"

"No," he responded. And he really didn't. Wasn't that strange?

Honest emotion: Dissed

Architectural Plans

*The only real valuable thing is intuition.
~Albert Einstein*

Architectural plans were spread out over Russ's desk. His head was down in deep thought as he studied the drawings. He was responsible for an expansion wing at our local church and for coordinating with the architect. It was a long-awaited, exciting venture.

Did I notice the erratic planning meetings, Russ's struggles with analyses, and his rare, uncharacteristic communication snafus? Yes, vaguely. But did I give them serious thought? Not really. For what was there to latch onto? Situations were too random and subtle to warrant a what's-going-on-here mindset. And after all, hadn't Russ been selected to lead the project because of his competencies? The mission was being fulfilled, and results were coming in as expected. All was well.

So, why did something keep nagging at me?

Honest emotion: "Off"

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VI. In the Throes

A Five-Year Journey

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Sample:

**Excerpt of
Section VI**

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Confession

The will to do, the soul to dare.

~Sir Walter Scott

An Alzheimer's support class. Should I go, or not? It would probably do me good....

I took the leap. The room held about a dozen people, estimated ages either fifties or eighties. After opening chitchat, the facilitator asked about our plans in handling our loved one's ongoing health. A packed question for sure. Luckily for me, she started on the opposite side of the room.

The elderly in attendance were mostly spouses. In general, they received comfort and companionship from their loved one and wanted it to continue, no matter how compromised the spouse's health. Quantity of days mattered.

The younger group were mostly adult children representing parents. The deterioration and loss of dignity for their parents was painful to watch. Hiring caregiver services was distressing, and they worried about their parents' emotional state of mind. Quality of life mattered.

This disparity left me uneasy. Perhaps it was my age, sandwiched between the two groups, that made me feel out of sync. Yes, I was a spouse like the elder members, but my philosophy aligned with the younger generation. My mind started buzzing. I felt unsure. What dare I reveal?

When my turn came around, pumped up self-talk said, *Be honest. Be brave. This is why you're here.* "Our family has decided on palliative care only. My husband would detest being as he is. Except for routine health matters, we're letting nature take its course with a pledge to keep him comfortable. Prolonging a terminal illness destined for a cruel ending feels crueler. We hope he peacefully goes first from something else."

"*Whaaat?*" came a bellow from across the way. "Are you saying that because my wife has diabetes, I shouldn't give her insulin?" I froze. The room fell awkwardly silent.

Then followed, “You’re saying that if your husband needed medicine, you wouldn’t give it to him?” Horrors, what was happening?

The room blurred. My face burned with embarrassment and humiliating judgment. Why had I ever chosen to come, to open my mouth? The guilt that’s ever present in caregiving, the feelings of inadequacy, the self-questioning of decisions, the burden of playing God with your loved one’s life—all came roaring into my heart and my head. In this room of strangers, my fragile confidence snapped like a twig.

Honest emotion: Judged

Introvert

*Introverts are deep, delightful, and yes...normal. Try us.
~Unknown*

The phone rang. My heart raced, muscles tightening. It was a close friend on the line, yet I didn’t answer. What was wrong with me? My friends had learned of Russ’s diagnosis and knew I’d be struggling with its implications for our lives. So, what was up that I couldn’t latch onto their outreach?

Well, my friends, you were right that I was struggling, and yes, badly. And that’s exactly why I couldn’t take the call, couldn’t talk, couldn’t “go there.” Emotional distress always shot me straight into hibernation, a classic introvert behavior. Behavior so predictable one could wager on it, yet it remained puzzling and worrisome to my extroverted friends. And the worse my distress, the longer I hibernated in my safe, alone cocoon to deal and to heal.

But how to explain this little-understood and oft-unaccepted phenomenon? Even to be okay with it myself? Although I knew it was normal, I didn’t like being that way. When friends wanted to help, to drop by with a comforting hug or offer kind thoughts, I wanted to be able to embrace and share. Instead, I’d freeze the moment interaction became necessary. The very thought was paralyzing. So, what did I do? I retreated.

My emotions were so raw, so deep and painful that I needed to protect myself. I wasn’t ready to raise my emotions, to talk about my most private thoughts and feelings on the devastating journey ahead. I first had to come to grips with the certain future for Russ and me. I needed to figure out our path and believe we could make it through the ordeal awaiting both of us. And I could not, could not, feel vulnerable.

I was overdue to accept that this modus operandi was simply me being me, the way I ticked along in life. Friends knew I’d surface in time

and perhaps even send a one-step-removed note in the mail. But in the meantime, full force hibernation was going down big time!

Honest emotion: Hibernating

Lost 'n' Found

*Lost and found: the world's most confusing treasure hunt.
~Unknown*

Where *were* all the washcloths? How could they just poof, disappear? And where *were* all of Russ's underwear? Seriously, where could they be?

I never got over the surprise of finding things missing due to Russ's slippery fingers. And the more so because I never saw him snatch and hide. I knew he liked to move items about, but disappearing belongings could be of any size and serve any purpose (from coffee mug to garden rake). A friend whose husband had dementia, and who encountered similar mysteries, swore there must be a massive storage shed bulging to the rafters and floating incognito somewhere overhead.

Not until several years later, when I packed to move, did some of the missing materialize. Russ's long-lost razor had been wrapped in a washcloth and stuffed deep in the toe of an old winter boot. Our camp keys, mysteriously missing from the car's glove compartment after the four hour drive from home, were hiding in a bookcase. And Russ's infamous long-lost sunglasses, covered with dust, had been tucked tightly behind his idle computer monitor.

The hidey spots were amusing in hindsight, but missing items unfailingly pushed my buttons. It meant hunting, endlessly and everywhere, all the while eagle-eyeing Russ for new mischief. And if *his* special something was missing? Forget it! His agitation, and my stress from the search, left my patience and emotional energy deep in negative territory.

I needed to be like a superhero with multiple magic eyes that could penetrate *all*. Then, by golly, that lost razor in that old boot would have been found snap, snap, *snap!*

Honest emotion: Out of patience

Alaska, Part One—Arrival

*Never test the waters with both feet.
~Proverb*

Alaska? You want to go to Alaska? Holly and I stared at Russ in utter surprise. He nodded, retreated to his study, and returned with an Alaskan cruise brochure. Man, who knew?

Come to find out, Alaska had long been on Russ's bucket list. This from a man who preferred homelife and little travel. So, with little time to waste, Holly and her husband Pete, Russ, and I became Alaska bound. I knew travel could exacerbate dementia's confusion but believed he could manage a cruise. He'd be in one place, and we three could handle anything unforeseen. We had adjoining rooms and Russ his all-important TV. I was confident we'd breeze through just fine. This was going to be fun!

Our long flight to Anchorage went well despite a few glitches in keeping Russ apace. We'd reserved a day to explore the city, and Russ, though game, was quietly detached. I wasn't worried, though. Nah! We'd soon be settled aboard, and Russ would be living his dream!

We found our rooms mid-tier on the ship. I couldn't wait to check out the amenities, the layout, the scenic mountain views, and the food courts (yum). I turned excitedly to tell Russ to come look out the window and...but, where was he? I rushed into Holly's room. Was he there? No. I rechecked our room. Nope. He'd vanished. I grabbed Holly, and we ran to the foyer, frantically searching for his familiar plaid shirt and blue jeans. I panicked we'd never find him if he'd wandered off to who-knew-where on the massive, multi-deck ship. Ooooh, far across the way in a throng of bustling passengers, could that be him? Yes! There he was, casually strolling as if he'd nary a care in the world. Thanks be.

"C'mon, dear," I gently urged, as Holly and I approached. He looked at us blankly, confused and unsure. In a calm voice conveying okay-ness, I assured him, "All's fine, dear. Let's go back to our room."

With a stab of concern, it dawned on me the trip might not be as easy peasy as I'd imagined. Sure, Russ's behavior had been off since leaving home, but I'd simply attributed it to fatigue. Had I been crazy naive? The seven days to come suddenly loomed disconcertingly ahead.

Later that evening, Holly asked that we go to the laundry room. In the private tiny space, her pent-up distress and disbelief about her father's condition broke free. She'd been shielded from the reality of his burgeoning decline by not living at home, and he'd deceptively rally his behavior whenever she'd visit. At that excruciating moment, in that cruise ship's laundry room three thousand miles from home, Holly was reconciling to the devastating truth about her father's illness. It was beyond heartbreaking.

Honest emotion: Unexpected

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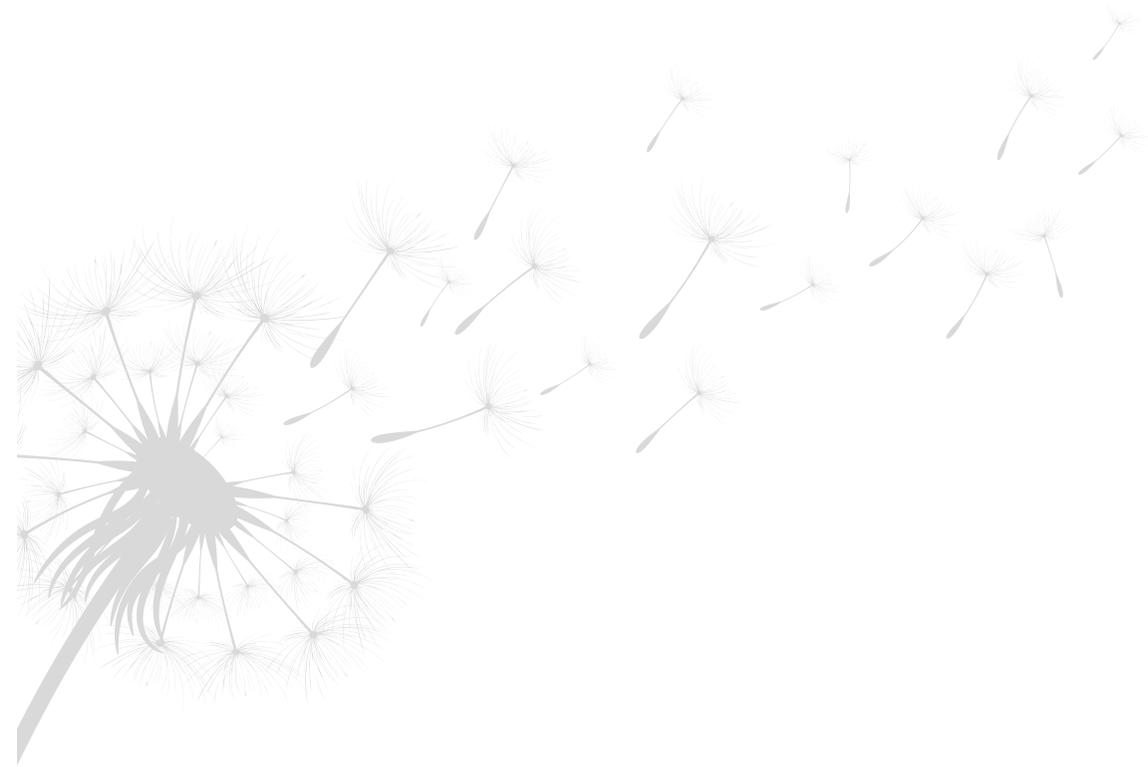
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VII. Breaking Point

A Three-Month Journey

**Excerpt of
Section VII**

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The Move

Hope is a waking dream.
~Aristotle

Text to Russ's sisters:

Hi Priscilla and Carrie,

This has been such an emotional week. I can't believe the move has happened, but the decision feels right in my gut. Rusty [Russ's family nickname] has adjusted to the new house quite well. I've kept fixtures and furnishings much like our old house, which has helped. He's getting to know his way around and is happy to return after our outings. It feels wonderful to be near the girls and help if needed.

Heidi has taken Dexter back home with her. His diabetes is under control, and we're close if anything arises. I miss him, but the house is quieter and easier with one less loveable "lug" to maneuver around.

I believe we're seeing the natural progression of Alzheimer's... sundowning, restlessness, agitation, attempts to wander, refusal to shower and change clothes, swearing, and more volatile behavior. Many of these behaviors were happening before the move, but that has probably exacerbated them. He's been on a plateau for a while, so these should not come as a surprise, even though they do. Weird, huh? I'm trying to stay positive.

Love you bunches, and I'll keep you posted...Dale

Honest emotion: Treading water

The Closing

*Wherever you go, go with all your heart.
~Confucius*

This was an episode for the ages. The closing on our house was at eleven o'clock, an hour away. To my chagrin, a change in date nixed Linda's availability to watch Russ. Oh, well, we'd make do. He and the dog would just have to join me.

Russ was still edgy from the recent move, but I put my trepidations aside, and off we set. The big dilemma ahead? Russ would refuse to accompany me into the building. But if I could find him a distraction, and with Buster for company, he might be okay alone. But what? Food! Russ loved food, so with scant minutes to spare, I swung by a convenience store for pizza slices and a soda. That should do the trick.

The hour arrived. I parked at the far end of the lot to minimize distractions. It was winter, and a snowbank served as a barrier to the gully just beyond. Yikes, I'd forgotten about the temperature. Russ detested being cold. Did I ever dare leave the car running? Could I really do that? Oh, the pressure! I had no choice; I'd just be quick. With my frazzled caregiver brain about to explode, I said, "I'll be back in a minute, dear. Stay right here with Buster."

I found the realtor in the conference room, but no buyers. I quickly explained I'd need to check on Russ every few minutes. We waited. Small talk. We waited. Nope, I couldn't stand it, had to check on Russ. I slipped out and headed to the car. My mind felt strange, fuzzy. Where was the car? *Where was the car?!* I raced to the gully. Nope, oh, thank God. *Oh, no!* Russ had driven off with the dog!

I flew back into the building. "Call the police. My husband has Alzheimer's and drove off with the car! Our dog's in the back seat." In a flash, the entire realty staff mobilized, rushing toward the street, and fanning out in both directions. In disbelief, the realtor and I waited outside

for the police. A young couple who'd waited for the crowd to disperse started toward the building.

"Hi," I said. "Did you see a man driving a white SUV leave the parking lot with a dog in the back?"

"Yes, he just drove by, smiled, and waved to us." (*Russ, you silly man.*) "But I didn't see which way he turned." Crap!

We waited for what seemed eons. Suddenly, one of the realtors spun back around the corner. "We found him. Three blocks down. He's parked at a pediatrician's office. He was inside trying to exit a back door into the woods. The dog is safe in the car." OM dear G. Thank you. All were safe. No one harmed, no wrong way crashes on the highway. We followed the realtor to fetch Russ, but there, jauntily walking toward us down the street as best buds, were Russ and a plainclothes policeman. Russ was glowing. Cheery. Smiley. Mega-joyride happy!

I retrieved the car and the dog, then returned to the realty office. Russ was amped. Smooth as butter, the realtor caught his eye and offered up a hot cup of coffee (i.e., food) inside the building. A temporarily altered person, he followed. I couldn't sign the paperwork fast enough. Upon leaving, I offered best wishes to the new owners, the astonished "friends" Russ had cheerily waved to on his exit. We walked to the car with a dizzying, surreal air enveloping what was to have been an ordinary but celebratory day. Buster awaited. I started the joyride car. We three headed south to home like nothing at all had happened. Nothing at all.

Honest emotion: Surreal

Daycare, Part One—Hope

*But what we call our despair is often only
the painful eagerness of unfed hope.
~George Eliot*

Russ would benefit from an Alzheimer’s adult daycare program, I was positive. As for me? It should have happened many yesterdays ago! Daycare centers were not plentiful, so the search had been expansive and stressful. But there, at last, were Russ and I, seated at a dining table at an Alzheimer’s daycare, his first look-see of the facility.

Suddenly, the slow, accentuated sound of, “Hello, dearie” wafted across to my ears. I turned toward the voice, just in time to see the source bend down in front of Russ’s face and ask, “Dearie, would you like a cup of coffee?” in the same sweetie voice as before. Was this a spoof? Russ had Alzheimer’s, but he still had his dignity. Wasn’t it possible to approach Russ with an ordinary, “Hello, sir. Nice to see you. May I get you a cup of coffee?”

Well, I was likely being too sensitive. *Keep an open mind*, I reproved myself. We joined the participants in rowed chairs facing a staff member holding the day’s newspaper. The leader asked if anyone knew the day of the week, and the date. *Ooookay*, I thought, as I scrambled to recall it myself. She moved on to the weather. Could anyone describe it? No. From there she proceeded to read the day’s headlines. Looking around, all I could see were expressionless faces with zoned out stares.

About a half hour into the monologue, came sports. By now, heads were nodding low on their chests. Finally, leaving the best for last—the classified ads. *The classifieds!* Ohhhh my gawwwd! Was this a daycare parody? Job listings, lost pets, houses for rent or sale. I could’ve collapsed from no-pulse-boredom. Lord, help us all.

Music followed. *This should be fun*, I gambled. Something adding some zip to the morning! My expectations popped like a balloon, however, as

the uncommunicative guitar player droned away, while staff segregated to a far corner to chat.

For sure, Russ and I were in the twilight zone. He’d sat quietly throughout the morning’s ordeal, but I was mentally warped, my mind twisted, incapable of grasping the unexpected experience. Grabbing Russ, I excused us and reached the car in a blur. I was desperate, desperate for respite from 24/7 caregiving. Desperate for a program to save my sanity, but this one? *Never!*

My joyous expectation of longed-for daycare relief turned to bleak, dark despair. Hope flattened like a pancake. Whatever would I do now? How could I make it through? I was really, truly, all alone to manage all alone. I could have crumpled to the ground, as despair drained my soul.

Honest emotion: Forsaken

Daycare, Part Two—Nope

*No matter how much you push or twist, it just
won't fit. It's all right to stop trying.
~Unknown*

Several days later, in a last-ditch hope of salvaging daycare, Linda agreed to accompany Russ for another try. Too much emotion still filled me to do it myself. I nervously watched as the twosome headed down the road, and out of sight. My Pollyanna fingers were crossed that this day be utterly stupendous.

Before lunch, uh-oh, there appeared Russ and Linda coming up the drive. A bad omen, for the daycare was some distance away, making it way too soon to be back. Dread seized me. They piled out of the car, and Linda's face gave no doubt that things had not gone well. I whipped up a quick lunch and settled Russ in his trusty recliner with the TV, a nap coming after his out-of-routine morning. Linda and I had serious matters to discuss.

She spilled the goods. "After an hour and a half, I couldn't take it any longer. We had to get out of there. Russ looked so stressed, I thought he might vomit. They were patronizing and had nothing interesting for him to do." Her voice was thick with held-back tears. "The lady asked, 'Oh, isn't he having a good time?' as we put on our coats. I said, 'No!' and we walked out. When we got to the car, he grabbed my arm tight in thanks. It was awful." My heart went out to her, brimming with understanding and love for her willingness for one more go.

Well, we had our answer. Russ would not return. Reflecting back, I believe he was simply a poor match for the program. Most participants were sedentary ladies in their eighties, and activities were geared to their interests and skill levels. Russ was healthy, active, and needed stimulation from hands-on activities involving manipulating objects. Being handed a pre-pasted paper cat to place on a blank piece of paper wasn't doing it.

The real problem? A dire need for early-onset dementia programs for folks like Russ. Centers with activities that meet the needs of a younger and more robust population. Centers with activities and supplies appropriate to the interests of all genders. This is an overlooked opportunity with ready participants. Let's go, entrepreneurs!

Honest emotion: Misfit

SAMPLE ONLY

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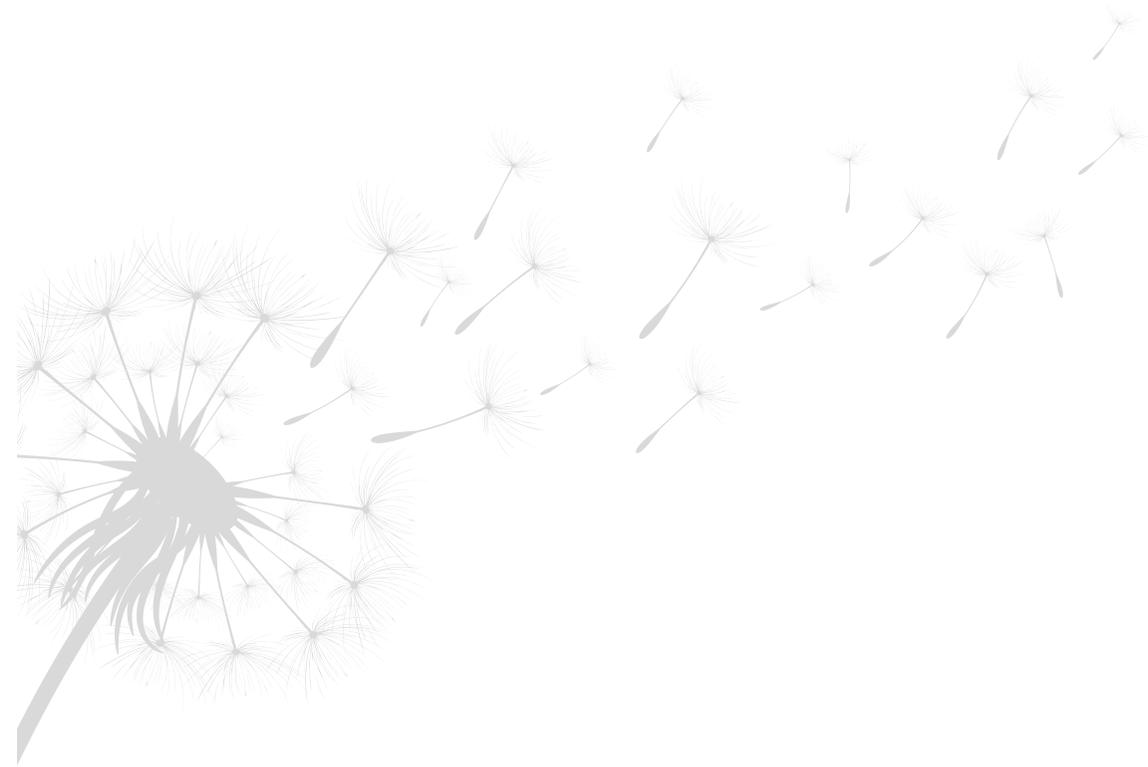
Sample:

**Excerpt of
Section VII**

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**VIII. Placement One,
A Broken Heart**

A Three-Year Journey



SAMPLE ONLY

The Never-Wanted Day

Even the darkest night will end and the sun will rise.

~Victor Hugo

Monday, January thirteenth. The sun rose, and I was still breathing. There had been times I was certain placing Russ in a facility would surely kill me. But it hadn't, for there he and I both were, alive and upright. After all the grueling research, facility visits, administrator chats, red-tape approvals, and financial discussions (oh, the killer stress of it all), Russ was going to assisted living at Spruce Haven Dementia Care. Despite being an hour away, it met all our criteria and offered continuing care services.

I anguished over how to explain Russ's stay to him in a way that wouldn't turn him defiant and combative. After umpteen phone calls and a strategy meeting with Spruce Haven, the plan was hatched. Our idea? A ruse. Russ would attend under the pretext of receiving speech rehabilitation, appropriate, since he acknowledged that speaking gave him trouble. So... we attended a meet-and-greet luncheon to test the waters, and kudos to Russ, he sailed through like a champ! Me, I had to focus on not upchucking from worry over his state of mind and possible disruptive behavior.

D-Day. Spruce Haven admittance was at ten o'clock. Holly and I tried to relax as we drove Russ to the big check-in. Linda and Heidi followed after discreetly loading Russ's recliner and personal belongings. The plan was that, during Russ's check-in, they'd quickly set up a cozy looking room with his favorite pictures on the walls, the woodland comforter on the bed, and his recliner ready and waiting. All in hopes of easing the transition and reducing his trauma.

Admittance was complete. *This was it.* Dread flooded me. With pounding hearts, Holly and I casually walked Russ to his room, each step jangling my nerves raw and tossing about my insides.

The room looked fabulous. His reaction? A non-reaction, his calmness a jolting but pleasant surprise. For all the angst in preparing for this

wrenching day in every way conceivable, the scene was nothing as I'd envisioned. No balking, no confusion, no agitation, thank God no crying, just a strange, vacant nothingness. My mind faltered with the welcome but shocking reaction, thrusting my mind into an upside-down, surreal state of bizarreness.

Russ and I locked arms and walked the floor, checking out this and that, while I procrastinated leaving. Finally, there was nothing left but the goodbye. With my chest bursting from stress, and lungs burning for air, I gently told him he'd be staying for a bit to receive help with his talking—just like we'd discussed—and I'd be back. I cheerily kissed him with assurances of my return. Paralyzed emotionally, I turned and walked stoically out the security door, the clink of its lock sounding behind me.

Holly took over strolling until an attendant approached to distract her father. Without incident, Russ obediently took the staffer's hand, turned, and nonchalantly they walked away together down the hallway, all as if an everyday occurrence were underway. The deed was done. It was over.

The girls offered to stay the night, but I craved solitude to release my stress and process the day. A quick call to the nursing station confirmed Russ was not, in fact, distraught, and was adjusting beyond expectations. Truly? The absolutely most divine, but unexpected, news possible, but I was baffled. Where were the protestations, the stubborn defiance, the emotional outbursts I had been sure would erupt? Could he really have lost that much cognition to be oblivious to his situation? Perhaps he was totally overwhelmed? Perhaps neither or both, but whatever the reason, Russ appeared surprisingly settled. I sank to the couch in immeasurable, blessed relief.

I crawled into bed. Staring into the darkness and listening to the silence, I offered up thanks to the universe for a bad day having gone well. With the dog next to me, I pulled Russ's pillow close and hugged it until sleep came.

Honest emotion: Beyond dread

First Visit

*Surprise is the greatest gift of which life can grant us.
~Boris Pasternak*

So incredibly hard. Spruce Haven preferred we not visit Russ for a week, to ease his adjustment. I felt raw. I was heartsick for him, certain he felt abandoned and confused. This whole nursing home placement gig was a b*tch, believe you me!

I called each morning and evening. The girls and Linda did as well. We each shared our news, but nothing beat the comfort of hearing the confident, reassuring nurse's voice on the other end of the line. We never felt we were pestering the staff, only welcomed.

Holly volunteered to visit her father first. My nerves were so on edge about him looking distressed that I needed her to do the deed. So away she went, inside the "demon" doors of dementia care. I waited outside, hands clammy, chest full of pounding anxiety. It seemed ages before she popped back out. I scrutinized her face for the teensiest, weensiest telltale sign of bad news she might try to shield from me. But her face was...gee...okay! Sure, lots of emotion, but nothing indicating horrible new heartbreak and torment.

Relief rushed through me. She'd found him calmly walking the halls. He'd brightened at seeing her, and they had walked, linked arm in arm, Holly making light conversation. The nurse said he was adjusting exceptionally well, and again, when it was time for her to leave, offered Holly distraction. It worked, hallelujah, amen. No attempts to follow her, no apparent anguish, no banging and hollering on the closed door, the haunting fear I knew I could not bear.

For the first time since contemplating dementia care, the girls and I felt a glimmer of relief. He was adjusting well. Holly's visit had been a success. The staff liked him. Maybe, just maybe, he was settling in sooner

and smoother than anticipated. Thanks be to the lucky stars shining mightily down upon our broken but healing family.

Honest emotion: Sheer relief

Requests

*Nothing is permanent in this wicked world—not even our troubles.
~Charlie Chaplin*

It was nine o'clock on a sunny, cloudless morning. The phone rang as I sat sipping the first day's cup of coffee. Uh-oh. It was the nursing home. "Dale, we'd like your help with Russ if you wouldn't mind coming down. His pants are wet, and he refuses to let us change him." Staff, not wanting to upset his quick adjustment and overall acceptance of his new surroundings, hoped I could assist.

Russ was standing in the middle of the reception area, arms at his side, and face pinched with anxiety. The entire front of his jeans were soaked, down to his wet slippers. My heart swelled with love for him. Staff were hovering, and the scene had attracted a curious crowd. I ached for his dignity. Slowly approaching, I hugged him, and then looking right into his beautiful blue eyes, softly said, "Hi, dear."

His confused eyes focused on my face. We stood a moment in silence. Then I smiled, took his hand, and suggested we take a walk. We edged forward, linked arms, and slowly made our way down the hall to his room. "Gosh, dear. You're wet. Let's get you some dry jeans." I grabbed clean clothes and suggested we go change "over there," there being the notorious shower-room-that-shall-not-be-named.

Surprisingly, he walked without hesitation until we reached the entryway. "It's okay, dear, watch me." I turned to face him, gently pulling his hand, and backed myself into the room. He followed! He willingly undressed, but balked again at the entrance to the shower, tentative of the white tile flooring. Spotting a white towel nearby, I quickly laid it by his feet, abutting the shower stall. Gingerly he stepped onto the towel and then onto the white floor of the shower stall. Success!

Several days later, the nurse administrator called. "Dale, we've been assessing Russ the two weeks he's been with us. We believe he's a better

fit for the nursing home side of care. He's a dear to have around, but his needs are greater than we'd anticipated, and assisted living doesn't have the staff ratio to do him justice. We're requesting your permission to move him." My jaw dropped. Here I'd been agonizing that he wasn't advanced enough to even *be* at the facility. My silly imagination had them calling me to come fetch him. But this? Bam, a shocking biff on the side of the head.

Alzheimer's has no one-size-fits-all answer to care. No magic meter pointing to where one should be placed. No nifty clock showing when that placement should come. Alzheimer's is a crap shoot. And there's no cheating the dice.

Honest emotion: Caught off guard

Solo

Those who fly solo have the strongest wings.
~Mahatma Ghandi

When Russ transitioned from our home to the nursing facility—wow. For the first time in nearly fifty years, I was by myself. Only me rattling around the house. It didn't take long for folks to start asking, "Dale, how are you doing managing alone?" "Do you mind going places alone?" "Gee, are you scared being alone?" Even the blunt, "Would you marry again?"

All this *alone* talk, I didn't like it. It made me feel thing-y, as if my whole person were shrunk to a single dimension. It bothered me, but why so much? After all, people were only showing concern for my welfare.

First off, I disliked being categorized—and sure-as-heck not into sets of "alone" or "not alone." *Alone* seemed to connote something lacking, and I didn't lack Russ. Russ was still living, I was still married, still emotionally connected to him. Being labeled as alone removed him from me.

So, I changed the rules. Me? I was "solo." The way I viewed it, alone was a passive condition, as I lived in my house alone. But solo was a living action, as I lived my life solo.

Neither Russ nor I would be alone until one of us passed.

Honest emotion: Pigeonholed

The Paradox

Caregiver passes away from caregiving.
~Dale Sherburne

“I’m pulling no punches here, Dale,” said the doctor. “Unless something changes, you’re going to have a heart attack.” I stared at her face, serious with concern, as she held my medical records. Unfamiliar fear jolted through me. I knew my wellness exam was years delayed, for life had been too difficult to pull it off, but cripes. The good health I prided myself upon, the sturdiness passed down from my lineage—where had they gone? *A heart attack?*

“It’s that bad?” I croaked out.

“Yes,” she confirmed. “A heart attack or stroke, and believe me, you want neither.”

I knew I was overweight (thirty pounds of downed comfort food) and my waistline extra pudgy from the effects of stress-induced cortisol.¹⁹ But little did I know about my high blood pressure, nasty cholesterol levels, elevated triglycerides, wacky liver counts, lowered immune system, and my body’s inflammation level that was off the chart into the red pit of danger. *Holy cow!* I guess I was a mess. Yet I gaped at the impossibility of the downfall of healthy ole me.

What had happened? I’d just become another Alzheimer’s caregiver Hidden Patient²⁰, one among millions, who forgo our own health in order to meet the demanding challenges of 24/7 caregiving for our loved one. Behold the grim statistics:

- Family caregivers have a 63 percent higher mortality rate than non-caregivers, and of those, 40 percent die an average of two years before the Alzheimer’s patient they care for.²¹
- Women who care for a spouse, for nine or more hours a week, have their risk of heart disease increased by 100 percent.²²
- Older persons caregiving for a spouse/partner with dementia are six times more likely to develop dementia themselves than their non-caregiver peers.²³
- Three years is the average time for the caregiver’s weakened immune system to recover after caregiving.²⁴

Staggering ramifications. Alzheimer’s tentacles viciously ensnare caregiver minds and bodies, caring not upon whose life’s blood it squeezes.

Can you even believe this?

Is any part of this picture acceptable?

No. Let’s get to work.

Honest emotion: Inexcusable

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