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INTO
THE VAILEY OF
SHADOWS

OUR JOURNEY THROUGH ALZHEIMER'S DISEASE

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OUR JOURNEY THROUGH ALZHEIMER'S DISEASE

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Prologue

Alzheimer's disease is the most common disease of several under the larger umbrella of "dementia." Currently in the USA over 6.5 million people have been diagnosed with Alzheimer's disease. It is a chronic, progressive and ultimately fatal illness of the brain that relentlessly erodes its functioning. It is diagnosed more often in women than men, generally late in life. It may last anywhere from several years to 15 or more and has accordingly been nicknamed "the long goodbye." Half the time, in fact, the afflicted one outlives their spouse. The disease manifests itself differently from patient to patient. Some have hallucinations. Some wander away from home. Some become aggressive. Some utter profanities. It is a fearful experience for the patient, and even the more so for the spouse and the extended family.

The story that follows chronicles the course of this illness in one family. Perhaps by sharing it, I can help you better understand the nature of this illness and its challenges, share ideas for coping with the changes it brings, and encourage you to have hope looking ahead.



CHAPTER ONE

The Sunlit Lands

The books I read to our children years ago frequently touched me in unexpected ways. Let me share one story from *The Chronicles of Narnia*.

The great lion Aslan sends the two children Jill Pole and Eustace Scrubb to find a lost prince in the land of Narnia. Their travels, narrated in *The Silver Chair*, eventually lead them from their familiar “Overworld” to the subterranean “Deep Realm.” In this dark, nearly soundless place they meet a host of sad-faced gnomes gazing mute at them and other creatures who appear to be in a deep sleep. The Warden who greets them repeatedly says, “Many come down, and few return to the sunlit lands.” While there they encounter the witch-queen of that realm who almost persuades them that the sunshine of Overworld was only a dream. But even there in the Deep Realm, as Jill and Eustace finally discover, Aslan still rules, and he has not forgotten them.

My wife Sue and I have experienced a parallel journey stretching over 50 years. After traveling for most of our lives in the familiar sunshine of young marriage, family and careers, we have descended into a darker place, a Deep Realm that seemed to open right beneath our feet. Here many walk softly and slowly through an unfamiliar and often frightening landscape, a place of forgetfulness called dementia. Ours has been a journey of increasing silence and sadness that makes it hard to remember the brightness and warmth of the sunlit lands.

There will be no going back for us. It’s a journey we must make, one in which we need considerable help. The Bible uses another vivid metaphor. The Psalmist speaks memorably of “the valley of the shadow of death” (PSALM 23). All roads eventually converge in that valley. Whether we arrive there courtesy of illness, injury, or the accumulated infirmities of old age, all of us must pass through it.

We began quite literally in sunlit lands. We married on a day of bright sunshine in 1968 in Indianapolis. I remember it as a happy blur, a day of joyful celebration. Two hundred relatives and friends heard Sue’s grandmother Ethel sing “Savior, Like a Shepherd Lead Us.” They listened as Pastor Koenig read the sonnet by Elizabeth Barrett Browning which

Sue had chosen for our recessional down the aisle of University Heights EUB Church: “How do I love thee? Let me count the ways.”

That evening we rode starry-eyed in our gold Ford Fairlane toward our chosen honeymoon destination in Michigan. Suitcases safely stowed aboard and the camera ready, we drove quite literally out of the warmth of home into unexpectedly cold weather by Glen Lake. More significantly, we drove out of the dream world where marriage so often begins straight into the disillusionment one writer says invariably attends newlyweds.

Sunlit lands? In truth, the new territory of marriage could better have been described as partly cloudy. Clouds of selfishness and ill-temper frequently obscured the sunshine in our early years, but those failings did not derail us. We knew that we were two sinners trying to make a life together and that some disharmony was guaranteed. For the most part, life was still good. After the honeymoon we moved to St. Louis where I enrolled at Concordia Seminary and Sue took a position teaching second grade in Webster Groves. My studies and her teaching preparations made for late nights and inadequate sleep. In my final year of seminary our first child arrived, adding the challenge of parenthood. We were shaken by our first serious fight but survived it. I finished school and was ordained at my home church. We put our shoulders into the mission assigned us as pastor and wife. We reared three children. We pushed our way through disillusionments.

Our ministry itinerary brought us to five stations where we spent our lives immersed in the joys and sorrows of others. While I preached, taught, visited and busied myself at meetings and record-keeping, Sue found more than enough to fill her days, beginning with the daily labor of caring for our three youngsters. She became the director of a children’s choir, a ministry that continued for 30 years in four churches. In Sequim, Wash., she took on the role of church secretary and worked in the office with me. In Oregon City, Ore., we led marriage retreats at the coast. Life was full together. Her radiance buoyed me up whenever melancholy threatened to take over. Her energy, like portable sunshine, kept us at the tasks when lethargy or self-absorption threatened to eclipse my joy. Her exquisite soprano voice was the golden thread woven through our years.

At our final posting in Casey, Ill., the finish line came into view. As retirement neared, we had some decisions to make about our future course. By the time we arrived there, we were both 63 years old. Doctors had discovered blood clots in my lungs and later diagnosed intermittent cardiac arrhythmia. Those issues, along with chronically low blood pressure,

made me feel weak and faint. I envisioned throttling down to conserve my dwindling energy, so I returned to Concordia Seminary in St. Louis for an intensive two-week training course in intentional interim ministry. Such work was for a shorter term, I reasoned, and might allow for a relatively painless transition into retirement years. We were ready for that.

By that time, marriage was “better than it’s ever been.” That’s what I wrote to our children, all of whom were by that time grown, married and out on their own. We looked forward to the promised “sunny side of the street” that retirement would bring, with opportunities for longed-for travel, catching up with relatives and serving together in new ways.

But it was not to be. In 2014, our road took an unexpected turn out of the sunlit lands into the valley of shadows.



CHAPTER TWO

Road Signs

There were road signs pointing to our descent into that valley already years earlier. The earliest and clearest came to us through Sue’s father, Myron.

Sue and I had sometimes joked about the obsessive-compulsive tendencies she shared with him. Both of them loved precision. Neither could relax until the work was finished and plans for the next tasks well-laid. Myron manifested his compulsiveness most amusingly when he readied the trash for the burn barrel. All items had to be compacted, neatly folded in the barrel so as to take up the least space. Sue’s compulsion to perfectionism centered on her schedule and preparation for it. She approached her work in the classroom and later in her children’s choir rehearsals with a kind of exhaustive rigor.

In 1994, at the age of 78, Myron had an episode of confusion while driving home. The family thought he might have suffered a stroke, but no one recalls any further testing at that time to determine the cause. Less than two years later, he suffered head trauma in a serious fall on the ice at a gas station. Within weeks, he manifested significant memory erosion and more confusion. An MRI taken revealed a brain bleed, but doctors were uncertain if there was a connection with the dementia symptoms. Not long afterward he was transferred from their house in the independent living

area at Franklin Methodist Home to a memory care unit nearby.

This encounter unsettled Sue and me. We traveled from our home in Sequim back to Indiana and spent time with him. We had to learn how to navigate entry into his locked unit. The visits with him distressed us even more. How dramatically he had changed. He was silent for long periods. He could not clearly remember our names and his conversation was confused. He burst out with foul language. Occasionally, he told off-color stories of a sort we had never heard him utter. His musical ability remained strong, however. He could still play majestic hymns of the church on the piano — always by ear, not from music — even though he could not carry on the simplest dialogue.

Her father's rapid decline and his dementia symptoms troubled Sue, though she did not speak much about it. We could not visit often because we lived too far away. The demands of daily ministry absorbed us. Meanwhile, Myron did not recover but grew steadily worse. He died three years later in 1999, the same year my own father succumbed to cancer.

Sue quietly pondered her father's condition. During our years in Oregon City, she began to experience times of slight confusion that distressed her perfectionist nature. Instead of sharing those with me, she carried on an inner dialogue and wrote in the journals she kept, which I did not read until years later. "Is this the beginning of Alzheimer's?" she noted in more than one entry. On a 3x5 card she penciled "My Wishes." She listed two:

A clearer mind.

Mike as my husband for the rest of my life.

She had always had a "clear" mind. But now she struggled to recall details of a variety of things. After we moved to Casey, Ill., Sue began taking copious notes on phone calls so that she could relate to me what the callers had said. She also made lists of each day's tasks. And detailed grocery lists. And pages full of prayer notes for her daily quiet time. She wrote on cards, envelopes, scraps of paper, something I could not remember her doing so elaborately before. Curiously, it did not register with me for what it actually was — her attempt to fill in the holes as her mind struggled to remember things as it once had.

During those early years in Casey, our children began to see signs of change in their mother. Melanie noticed that Sue complained about frequently misplacing things. Glasses. A purse or wallet. Household items. Once during a visit, she seemed unaware the mealtime had come, something for which she generally made elaborate plans. On another occasion,

she retrieved some food that had nearly spoiled in the refrigerator and prepared to serve it. Melanie put all the observations together and confided her concerns about her mother's memory issues to her husband Gary.

Christa recalls hearing Sue say, "I wonder if this is how Alzheimer's starts." But it was not an easy subject to address together. "She was concerned about her memory," Christa summarized, "but if someone else brought it up, it made things worse." On a family gathering at Disneyland late in 2013, our son Peter and his wife Caroline were struck by Sue's seeming absent-mindedness during our days together, and by her forgetfulness of recent conversations. But when they attempted to share some concern about it, Sue resisted the idea that anything was wrong and they backed off. "They're adults," Peter told his wife. "Let them handle it as they see fit."

I did not see this as quickly as the children; I lived with Sue every day and found the changes too gradual to notice. What finally *did* get my attention was a phone call from a young woman who had been in Sue's children's choir in Sequim. Megan called now and then to chat with us. One day when I was alone in the house, she called and said she wanted to talk to me. "Is Sue OK?" The question surprised me, coming out of the blue. "Well, yes," I responded. "Why do you ask?" Megan said that the last time she had talked with Sue, something did not seem right. She sounded different. Unsure. Distracted in some way.

How was it that Megan noticed this and I didn't? I began to pay attention in a way I had not before, and I began to see what had been unfolding right before my eyes.

Something was clearly amiss. I felt troubled in spirit. Where was this road taking us? The answer came sooner than I expected.



CHAPTER THREE

Diagnosis and Decisions

Early in 2014, a woman named Carol in the congregation I was serving in Illinois confided to me that she wondered if she had the beginnings of dementia. "I've been forgetting things, and I even got lost driving home!" she explained. She told me that she had scheduled an appointment with a

neurologist at a clinic in Champaign, Ill. When I told her my concerns for Sue, she urged that we make an appointment for her there too.

We promptly set a date in March to see the neurologist. Champaign was 75 miles away, and on the long drive we pondered and prayed about what Sue might face. The doctor was welcoming and kind, and his intake interview was unhurried as he asked about the symptoms we had noticed. He examined her vision, her hearing, her reflexes and her coordination as she walked and extended her finger to touch his finger. He engaged her in conversation and attended carefully to her responses. Finally, he proposed a more elaborate “neuro-psych” test at the nearby hospital. It would take four hours at a minimum and give him a clear picture of her cognitive ability.

The testing took place shortly thereafter. Sue was outwardly calm and compliant as she endured a sequence of diagnostic exams while I waited and read in another room. Those tests, she reported afterward, were lengthy, but did not feel forbidding like college finals. The tests explored her ability to use words and understand their meanings, to lay out steps by which she might accomplish a project, and even to draw something simple, such as “What would the face of a clock look like at 4:30?” She was given a random string of words (“apple, ball, table”). Could she recall that sequence some minutes later after other questions had been interposed?

At the end of the testing, the doctor sat with us and shared results. “Sue, you did very well on most of the tests,” he began kindly. “But you had significant difficulty with the one that measures cognitive function, with your memory in particular. Based on these tests I can tell you with relative certainty that you have an early stage of Alzheimer’s disease.”

We heard the words. But their full import took a long time to register. We drove home in an emotional fog. I shared the results with Carol, who later learned that she did *not* have Alzheimer’s, only some distressingly similar symptoms, which grew fainter as time passed.

Sue’s symptoms, on the other hand, did not subside, even though the doctor had prescribed Rivastigmine (brand name Exelon Patch) as a preliminary medication. She still suffered from occasional confusion. There were still moments when names would simply not come. Sue still took copious notes on phone calls and made herself task lists and prayer lists. I noted some increasing weariness and a growing sense of dejection in Sue. She wondered, “Could I have done anything different that might have changed this?” I tried to reassure her: “I don’t think so. The doctors do not really know why some people get it and others don’t.”

At the suggestion of a friend, I checked out a copy of *Still Alice* by Lisa Genova, a book that portrayed a woman's descent into the shadowy world of early-onset Alzheimer's. It was a sobering splash of reality in my face. Though fictional, the story of Professor Alice Howland's progression into her illness described some of what I observed with Sue. It felt like a preview of what was coming at us in the years ahead. I prayed frightened prayers.

That August we celebrated Sue's 68th birthday. Despite my growing inner anxiety, life seemed close enough to normal that we could move on without any major disruption. Whatever was happening was blessedly gradual. But clearly, our imagined future would not be what we had pictured. I retired the next year, as planned, but I quietly abandoned the plan of being an intentional interim pastor. Instead, I became Sue's primary caregiver.

Already a year earlier, we had discussed with our children where we ought to settle down. Realizing we'd need special emotional and physical support to face this illness, we preferred to be near at least one of our children. But with them being so widely scattered, which one would it be? Our son Peter lived in the Bay Area of California and was busily employed by Google. His wife was a student preparing for a teaching career. They would not have the time. Nor would our daughter Christa in Missouri, whose life was a flurry of care and homeschooling for their six children. Daughter Melanie and her husband Gary lived in Gladstone, Ore., just a few miles from where we had lived earlier. Melanie and Gary married late; they did not have children and might be more available. They had already broached the possibility of our living nearby during a family gathering. Now that the diagnosis had been made, we asked if we might come west again to live near them.

"We'll need you to care for both of us in our old age," I said with a wry smile. They agreed, and the matter was settled. Our road map through the valley of shadows would eventually take us back to Oregon.



CHAPTER FOUR

Sunlight Yields to Shadows

As my retirement neared, one of the ladies at Trinity in Casey asked me if we might record some of Sue's solos. "I'll sure miss her singing!" she lamented. I was reminded of the recording of songs that Sue's friend Kathy had made before her death from brain cancer 20 years earlier, and I realized that this might be important not only for the folks at Trinity, but for me and our children too.

I contacted a local pastor who recorded his worship services. He agreed to help us. Our church organist consented to accompany Sue. A couple of weeks later, in just under two hours, we recorded Sue singing eight solos, including "O Holy Night," "His Eye Is on the Sparrow," "Goin' Home," and my favorite, the Malotte "Lord's Prayer." I am permanently grateful for those recordings of Sue's sweet voice.

When the day of my retirement arrived, it was simple, low-key, and love-filled: a worship service followed by a luncheon with a program. The church was packed with our own members and a generous helping of our own relatives from Oregon, Missouri, Indiana and North Carolina. Our daughter Christa and granddaughter Emily prepared five large poster boards with a pictorial history of our journey through 43 years of ministry. The kind folks at our little congregation showered us with generous gifts, cards and loving hugs. The following week brought a yard sale and very soon we were loading household possessions into the ABF freight truck that would transport them to the home that awaited us in Oregon City, Ore.

Our new home was lovely, and Gary and Melanie's nearness was a blessing, but it did not feel like "sunlit lands," especially to Sue. The relocation disoriented her worse than previous moves. Gone was the large home under the trees in Casey. Gone were our walks on familiar sidewalks to see the trains passing through town. Gone were the neighbors bearing little bags of produce. Who were these new neighbors? Where would we go to church? Where would we get groceries? Instead of the familiar IGA store a block away in Casey, we would shop at the big, bustling Fred Meyer store two miles distant. The busy traffic stunned us after living in our quiet little town in the heartland. Our old church in Oregon City had a new pastor and

new organist and many new faces just five years after we left. Sue felt like a stranger. “I hate this place,” she said after the move. Her negative attitude unnerved me. Sunlight had yielded to shadows.

Sue’s medications had no noticeable benefit. A few months before our move, the neurologist had taken her off Rivastigmine and prescribed Aricept and Namenda instead. But Sue’s unhappiness with the move and a general feeling of depression persisted.

Just weeks after our arrival in Oregon City, we traveled to the DMV to get Oregon driver’s licenses. The written exam did not differ much from other exams we had taken, but the outcome did: Sue failed her written test, and she was taken aback. She *never* failed anything. Not until now. “Let’s take a booklet and study it together,” I suggested. “We’ll do it again, and you will pass this time.”

But she didn’t. The second failure little more than a week later, even after some concentrated study, simply devastated her and reminded me that things had permanently changed. It marked the first notable loss of many to follow. I tried to joke with her that now that we were retired, I would be happy to serve as her chauffeur. She made it clear that she would definitely not be.

Her failed driving test reminded me to begin preparing legally for the inevitable changes, though I hoped such changes would not happen soon. In late summer of 2015, Sue and I saw an elder care attorney. We updated our wills, signed advance health care directives and filled in power-of-attorney papers.

At the same time, I looked for ways to bring light and laughter back to her. One that fell into our lap came from Martha, the woman who organized the singing group dubbed “Harmony.” Sue had been a regular member of the group for years before we moved to Illinois. Now Martha was on the phone. “Come back and sing with us,” she invited us. Sue began attending the monthly rehearsals and was glad for the renewed connections with old friends.

Other musical opportunities also came. Sue and I joined the small choir at Triumphant King Lutheran in Lake Oswego. Their small choir of six became eight, and we served the church and found joy. We also joined a senior citizens’ chorus that was performing for Christmas. It was heartening to sing together again.

We started a new venture also: a home Bible sharing and prayer group. We offered to host and invited former parishioners to join us Thursday evenings. Five of them were willing to make a start. We shared

our highs and lows, read the Bible together and discussed its application, and leaned on each other and God in prayer.

Sue still loved being with children. As autumn passed, we applied to volunteer together at a local school. We were accepted as helpers in one of the kindergarten classes. The perky teacher welcomed us brightly and put us to work. I exulted to see the little ones cuddle up to Sue.

Those were bright spots, but the shadows multiplied too. One evening well after midnight, Sue needed to use the bathroom. I wakened to hear her asking, “Where is it? Where is the bathroom?” “It’s right here, honey,” I told her. I got out of bed and turned on the light. The bathroom was just a few feet beyond the bed, but she could not find it. It was a preview of more significant confusion to come. The next day I put a night light in the bathroom, the first time we’d ever used one.

There was confusion also about relationships. Sue wondered aloud whether Melanie was her sister or her daughter. “Well, you don’t have a sister, so she must be your daughter,” I tried to explain. Another time, she began speaking of “Mike” in the third person, as if “he” were someone else, somewhere else. Quietly alarmed at this sudden disconnect from reality, I gently told her, “I’m Mike, and I’m right here.” Such lapses were blessedly infrequent, for now. Over time, they happened more often.

In August of 2016, more than a year after our move back to Oregon, Sue took her pet rat Nellie for a walk to the end of the block, as she sometimes did. But 15 minutes later, she had not returned. Remembering that dementia patients sometimes wander away, I felt a sudden fear and ran outside, looking both ways and calling out. She was nowhere in sight. “Maybe she took a longer walk up to the park,” I told myself. I got into the car and drove to the park — nothing. Then I made a circuit around the neighborhood. I did not find her. By now she had been gone almost half an hour. I called Melanie and Gary, who headed down immediately and joined my search. But it proved fruitless too, so we phoned the police and gave them a description. “Stay put,” they told us. “We’ll do a search.” A long while later, as it was growing dark, a friendly officer pulled up with Sue (and Nellie) in his patrol car. They had found her a mile away near a fire station in an area where we never walked. We had crossed over a threshold into a new, frightening reality. I felt more lost than she.



CHAPTER FIVE

Illusory Light and a Caring Heart

Alzheimer's disease slowly extinguishes hope. There is no cure, and the medications normally prescribed by traditional medicine have a minimal impact — or none at all — on the symptoms. It had been so for us. Sue was back on her original medication after finding that Aricept and Namenda increased her weariness and depression. We carried on a half-hearted debate about whether or not to continue using any meds at all. One day after a medical exam, she stopped and looked plaintively at me. “Why can't I be normal?” she moaned. I nearly wept. It became something much worse: “If I had a gun,” she told me, “I would shoot myself!” I never dreamed I would hear such dreadful words from my once-radiant bride. Those gloomy pronouncements made me step back and re-examine the medications Sue was taking. Should we persist with them, or do without?

Several friends, trying to be helpful, sent us articles with a variety of ideas about dietary changes and non-traditional medical ideas. Our daughter Christa suggested a homeopathic approach and sent a bottle of the pills. When I tried to give one to Sue, she asked what it was, and I made the mistake of saying it was helpful in the treatment of memory-related issues. She balked and would not take any more and thus ended our brief attempt at homeopathy.

During our first year back in the Northwest, we took Sue to see a nurse practitioner at Oregon Health and Science University (OHSU) in Portland. She was a bright, personable and caring woman in her late 40s. One day as we finished a routine exam, I asked her if there might be any clinical trials we could participate in. I thought that, at the worst, we could help gather information on possible treatments. There was a remote possibility that one of the trial drugs would prove effective. It was worth a try, wasn't it?

After the nurse practitioner explored the possibilities, she called a few days later to tell us about a trial underway for an experimental drug Saracatinib. The drug had originally been developed by AstraZeneca for the treatment of various cancers, but it had proved ineffective. Now the company wanted to see if it could be “re-purposed” for Alzheimer's. “It's a

double-blind trial,” she explained. “Some people receive the drug and some a placebo. We won’t know which people will get what. There’s no cost to you, but it will require a commitment to take the pills regularly and submit to scheduled exams and some brain scans. It’s a commitment of about a year.” Sue and I agreed to participate.

Our first scheduled visit happened in May of 2016. I drove the 18-mile drive to Portland’s South Waterfront and then into the massive underground parking deck beneath OHSU. Sue found the multiple elevators and various hallways daunting, but our nurse and her capable helpers put Sue at ease.

Each visit followed a similar format. We began with easy banter about how Sue and I were doing with daily life — mealtimes, sleep habits, and the ups and downs of our routine. Then came a physical exam which normally included such things as taking vital signs, tapping for reflexes, directing Sue to touch her extended finger and observing Sue’s brief walk down the hall and back. After the initial sharing and physical exam, Sue and I were separated and interviewed individually. For the later visits, we decided to bring Melanie along so that she could provide a different perspective, and I found that she often added insights I had not considered. I was pleasantly surprised at how often our nurse affirmed our instincts and encouraged us in our caregiving routines.

The clinical trial year was bracketed by sessions in which Sue underwent cranial PET scans to give the team a clear image of the physical progression of the disease. Those sessions were administered at OHSU’s hilltop campus nearby. Between exams we had nothing more to do but take the pills prescribed and note any effects they might make.

But there were no “effects” that we could discern, and I began to surmise that Sue was on the placebo. Nearly a year after the study ended in August 2019 we learned that was the case. But it would have made little difference if she had been on the drug itself. The clinical trial of Saracatinib demonstrated that it would provide no help for Alzheimer’s patients. The light we sought in the valley proved illusory.

Yet the time devoted to the clinical trial had yielded other blessings, chiefly in cementing our relationship with our nurse practitioner. All along the way, she proved to be a patient listener and a wise counselor. Melanie and I felt we could trust her wealth of experience when we had questions.

She helped us think of Sue’s progression in the disease in terms of three stages. The early stage brought mild cognitive impairment and confusion. The middle stage brought more severe loss of memory, changes

in personality and behavior, and the beginnings of incontinence. The third and most advanced stage brought loss of mobility, inability to communicate and finally the inability to swallow.

To our frequent questions about whether Sue's increasingly unusual behaviors were "normal," she often affirmed, "Yes, this is what I'd expect about now." Her encouragement affirmed us, especially when we felt like complete rookies at caregiving. When we finally began to broach the issue of placement, she eased the very natural guilt we felt in addressing it. She encouraged us to take the initial step of using an adult day care. It would be something good, she thought, not only for Sue, but for us in our emotional exhaustion. "The caregiver needs care too," she said.



CHAPTER SIX

Companions in the Valley

In the early years of Sue's illness, both the nurse and others advised me, "Make sure you take care of yourself." At the beginning it seemed unnecessary because Sue was still quite functional, even though confused at times. Nevertheless, I inquired about Alzheimer's support groups and found more than one. I settled on a group that met monthly at the local community center in Oregon City.

It was facilitated by a man who had recently lost his wife to the disease. Most of the time, he and I were the only men among the 10–12 people present. Strangely, even though Alzheimer's strikes women more than men, it was mostly women at the 90-minute sharing sessions. For the first few months, I was able to leave Sue at home to manage without me. Later I had to find someone to sit with her.

Though the facilitator sometimes distributed printed resources, we spent the bulk of our time giving each attendee time to share what was happening at home. It was a comfort to know I was not alone, that others faced issues that were often more perplexing than mine. "Shall I hide my husband's keys? I'm afraid to let him drive," one woman asked us. Several chimed in with thoughtful suggestions. I heard about fears of aggressive

or unpredictable behavior, a spouse who refused to take a shower and relatives who refused to acknowledge any problem at all. Since most had been caregiving longer than I had, I was furnished a preview of issues I would have to face, such as locking the home to prevent an exit, dealing with incontinence and weighing factors that might force a decision to place a loved one in a care facility. The group shared honest feelings and provided helpful ideas.

During our first year back in Oregon, I had connected with two people who were in my situation as caregivers. Retired Pastor Paul Schmidt's wife had been placed in a memory care facility. His listening ear had blessed me already years earlier. Now he shared his experience of caring for his wife, and I leaned on him emotionally. Former parishioner Marilyn Kolar cared for her husband Dick at home. Sue and I visited them there and were lifted by her good cheer. Months later she told me that she had begun taking Dick to Thelma's Place, an adult day care in Canby. Her description persuaded me to consider that for Sue when the time came.

We also received indispensable aid from our personal "gang of six," women friends of Sue who could be called on with a few days' notice to come and sit with Sue while I did chores or took a break. Often one would come for two or three hours at a time to sit and talk, take a walk or read stories. Martha, her Harmony friend, was one such faithful reader. She brought Sue *The Puffin Baby and Toddler Treasury* of nursery rhymes, songs and stories. Sue enjoyed hearing the familiar rhymes and sometimes sang along with Martha. Afterward, she took Sue to lunch. Those women blessed us incredibly.

Some who could not be physically present sustained us by their prayers or encouraged us with gift books. My friend Mark sent *Walking Through Twilight*, the memoir of Denver Seminary professor Douglas Groothuis, whose wife was stricken with primary progressive aphasia, a form of dementia that robs the sufferer of speech. His narration of their journey and his reflections on it made him feel like my partner in the valley and pointed me to the promises of God without sugar-coating the pain.

A steady dose of help came from Melanie. Each week without fail she made herself available to her mother. They made regular trips to the local fitness center for low-impact workouts. She gave Sue a sense of usefulness by taking her on walks through the neighborhood armed with a "grabber" pole and a plastic bag to retrieve pop cans, discarded wrappers and other trash. Inside the home she encouraged Sue to sweep the floor or iron the laundry, both tasks that Sue enjoyed.

Such companionship made the journey bearable and at times even joyful. We were not alone.



CHAPTER SEVEN

Thelma's Place

By the year 2017, three years after her diagnosis, I had become Sue's full-time caregiver. The day-to-day tasks that sustain every household fell to me as she lost her ability to do them. What I had done only occasionally now became daily responsibilities.

I shopped for groceries and prepared meals, and in so doing began to appreciate what Sue had done over the years for the family. The house did not clean itself, and clothes did not launder themselves; these reminded me of how much I took for granted. Getting Sue dressed each morning and undressed each evening required an extra measure of patience, and I had to learn unexpected lessons about slips, bras, hosiery, makeup and jewelry.

Marilynn Kolar's suggestion about day care began to appeal to me as my household duties grew more time-consuming. She spoke of the good care Dick received at Thelma's Place in Canby, seven miles south of our home. Early in the autumn of 2017, I took Sue there for a visit to look at the facility and meet the staff.

The large two-story home had an alley on one side and a fenced garden on the other. The dementia day care occupied the ground floor, and a preschool was upstairs. Three staffers busied themselves with a half-dozen guests for that day, each one of whom wore a clip-on nametag with his or her name and place of birth. The most memorable staffer was a large, cheerful woman of faith named Zori, a native of Guatemala. "Good glorious morning!" was her standard greeting, even if it was cold and cloudy outside.

We learned that the normal "day" lasted anywhere from 4–6 hours and included snacks, customarily served upon one's arrival, and later a lunch. It cost \$14.00 per hour or \$70.00 for a full day. Some of the guests came only once a week, others more often and a few daily. I agreed to bring

Sue, and since she was still able to understand some things, I asked Zori to call Sue a “volunteer” and give her some “helper tasks” to make her feel useful.

So began a long, pleasant association at Thelma’s Place. Initially Sue wondered where I had been when I returned to get her, but after a time she integrated well into the home’s fellowship. Often when I came to pick her up, she sat at a table with the others, engrossed in a game or craft. Once I found her and the others on the porch attired in snazzy hats for a photo session. The staffers were always kind and made their care fun and creative. Toward the end of the nearly two years we visited Thelma’s, the staff felt like part of our extended family. A bonus for us was the evident faith in those who were caregivers. They were, it felt, our sisters in Christ.



CHAPTER EIGHT

Deepening Darkness

Douglas Groothuis described his experience of caregiving for his wife Becky as “walking through twilight,” a journey that would eventually bring them face to face with “darkness.” That’s a good description of what the journey through Alzheimer’s has felt like to me. A twilight deepening toward night.

Each day, in fact, Sue became more anxious as afternoon wore on into twilight. As with many dementia patients, she was experiencing “sundown syndrome,” a time of anxiety that increased as daylight dimmed. Most often it manifested as an urge to “go home,” even though we were literally at home. Sue would go to the closet, get her coat on, and say with some urgency, “I need to go home.” Sometimes I was wise enough to enter her reality and say, “OK, let’s go,” whereupon I would get my coat too and take her for a walk, usually around the block, until we came to our own door. I’d say, “Here’s our house!” At other times, especially when we both had pajamas on, “going home” presented a problem, especially when the weather was cold. Should we get coats on over our pajamas? Could I distract her and set her mind on something else? That task grew more difficult as time passed.

“Does mom know where we are?” Sue asked frequently. At first, in my inexperience and ignorance, I tried to explain that her mother had died years ago. But the distress this produced, as if she had never heard the sad news, made it clear to me that I needed to walk alongside her in her world. So, after a time, I began saying, “Yes, she knows where we are out here in Oregon, but she and dad are far away, so I’ll let her know you are fine.” My intent was not to deceive her but to walk in her world, where dad and mom were still “back home.”

The deepening darkness brought increasingly bizarre behaviors into the daily routine. I could not let Sue out of my sight for very long, otherwise she might do almost anything. Items in the kitchen disappeared from their normal spots and wound up in the refrigerator or in another room altogether. I might find her in the bathroom with toothpaste on her face (as if she were applying cold cream) or earrings in her hair. If I were sitting at my computer trying to write something, she would suddenly appear beside me with almost anything imaginable in her hands, holding it out for me to “do something” with it. It might be a photo album or a recipe box or her bag of curlers. I soon began to sequester some things (like jewelry) in plastic bags where she could not easily find them. I tried to minimize my growing sense that our orderly world was falling apart.

For a while we still attempted trips to visit friends. But now and then at night, Sue would rise from bed, wander through the hosts’ home and wind up unannounced in their bedroom. Twice I recall our gracious friends bringing Sue back to me just as I was waking up to the realization that she was gone. Our visiting finally came to an end.

Because of her tendency to wander, I decided to change the locks on our doors to make it harder for her to slip out without my knowing it. She still managed to slip out twice more, each time requiring me to call the police for help. I was grateful for their patient kindness with both of us.

As Sue’s condition progressed, she began to balk at taking showers and washing her hair. A suddenly sharpened sense of modesty made her refuse to get undressed in front of me. Once again, Melanie came to the rescue by asking Sue to “help her” take a shower. This became a weekly routine for a time.

I realized that reasoning about things did no good. Sue could not process reasons. So, when I was at a loss for what to do, I’d put Sue in the car and take a “drive to survive.” Fortunately, she liked taking rides and did not often ask where we were going, so we might drive to a park or the town’s

promenade overlooking the river for a walk. We might head to Mike's Drive-in for an ice cream cone.

Sometimes, I confess to my shame, I was neither patient nor creative. The increasing chaos collided with my need for control, and my emotions unraveled into anger. I would shout at Sue, as if sheer force of words could rein in the strange behaviors. But my rages accomplished no good and left Sue asking fearfully, "Why are you saying this?" Why indeed, I wondered, feeling like a failure at this "final exam" of life.

At year's end I made the following entry in my journal:

The year 2017 was the hardest year of my life to this point. Sue's increasing disability with Alzheimer's has taken a toll on me emotionally and spiritually. I became a full-time caregiver for her, though often through clenched teeth.



CHAPTER NINE

Finding Refuge

The time came for me to consider moving Sue to a place where she could get full-time care. The first reason for my decision was Sue's *safety*. After years of talking through our disagreements, I saw that talking reasonably no longer made any difference. Very often at the end of the day she fixated on going out, and I attempted to persuade and ultimately forced her to stay and get ready for bed. Frustrated and exhausted by this routine, I grew angry. With increasing frequency my explosions of anger resulted in harsh language. I pulled off her sweater and shoes, shouted at her to get her pajamas on, and even wrestled her into the bed. My loss of control stunned and frightened me; I feared that I might be on the verge of serious abuse.

Increasingly, I feared not only for her safety, but for my own emotional *health*. The intensity of caregiving was ramping up, and it had proved exhausting and depressing to me, as it had been to many others. In addition to shopping, cooking, cleaning, watching Sue lest she exit the house and being confronted daily with bizarre behaviors, I had now

begun to purchase Depends briefs for her due to occasional incontinence. Diapering our children had been one thing, but cleaning Sue after an accident distressed me in the extreme. I found myself trying to give out of empty pockets. I had become a monster in the mirror. After a particularly dreadful evening when I shoved her to the floor and made her cry in terror, I sat at my desk in tears. This could not continue. In the weeks following, I made an appointment to see a counselor and try to get a handle on my behavior.

If I placed her in a facility, I would be a better giver while with her. But was I simply being selfish and abandoning my vow to love her “in sickness and in health”? Was I taking the path of least resistance? When I shared my uncertainty with our children, they felt such a placement might be necessary for both of us. No, they assured me, I would not be abandoning Sue. I would continue to care, but in times of shorter duration and more intensity.

But where could I place her? My daughter and I sought direction from All About Seniors, a free service that helps families find the place for mom that’s best. There we met the director, a nurse with wide experience in caregiving. After an initial interview she looked at me with kindly eyes and said, “I think you’re experiencing caregiver fatigue.” Someone had finally given a name to the pack I was carrying on my shoulders.

The director helped us develop a list of memory care facilities that offered good care, were reasonably close and had no serious complaints. Over the next two months, we visited 8–9 different places. All were nice, but costly (\$6,000 per month or more). We narrowed the list to three, chose one and placed Sue on the waiting list. I took Sue there for an occasional visit to get a feel for the routine and the staff. We ate a meal in the cafeteria. We attended an activity and watched residents and staff interact.

I would have been extremely anxious about the looming expense of memory care for Sue had it not been for some well-timed advice from our Thrivent financial advisor. Already years earlier he had suggested that we consider purchasing long-term care insurance. We finally bought two policies, one for Sue and one for me. The benefits of each one would extend for a term of three years, and the policies were transferable. The premiums and monthly benefits meant that, on the financial front, I could look ahead without anxiety. But finances were not the only issue. Was our chosen facility the right fit?

After 6 months of waiting, I grew uneasy with the place. It was 9 miles distant, and it felt like an elegant warehouse for people. Is that what

I really wanted? At the same time, my daughter said she had been told by several that we ought to explore adult care homes — family-sized places that had only 3–5 residents and a small, fixed staff. Relationships were their strength. It would feel more like a family. Once again, we began a search, aided by the director from All About Seniors. It took us into a variety of homes, some of which we visited twice. The key feature to me was the personality of the caregiver. Most homes were less expensive, but most also had no vacancies.

We entered a time of praying and waiting, and at last three vacancies opened, almost simultaneously. We arranged screening interviews with the primary caregivers. One said Sue would not be a fit at her home. The other two presented such varying styles of interaction that we decided with relative ease. Sue would be placed at Trinity Blessed Care.

And so Sue moved on August 1, 2019, more than five years after her diagnosis. The owner, a cheerful Filipino woman named Mina, impressed us with her affectionate care for Sue. She also shared with us that she was an active Christian, an extra blessing. Mina requested an initial period of two weeks of no contact from family so she might bond with Sue. It was our longest separation in more than 50 years of marriage. Painful! Then I commenced visits, usually for 1–2 hours in a day. This particular care home, one of two that Mina owned, was only a half-mile east of our own house.

In the first month Sue did not adjust well. The combined shock of a new place, new faces and a whole new routine would unsettle even the healthiest person; but for someone suffering with Alzheimer's, it's a greater trial. Sue alternated between placid and angry. She was often restless, trying doors, asking "Where did they go?" She slept irregularly, and in the afternoon, her "Sundowner's" kicked in, resulting in combativeness and a lashing out that endangered the staff. I was also concerned because the primary caregiver was not Mina but one of her assistants who seemed capable but less caring toward Sue.

I brought my concern directly to Mina, who recommended moving Sue to her other care home nine miles away, but under the supervision of Mina's sister Menchie. That solved several of the problems. Sue began sleeping more regularly, and she became more peaceful during the days. This house had more light and more people. Sue was one of five residents, and two of the others were women who interacted with her. There was more music, including a music therapist who came weekly to play and sing with them, and more love in the person of caregivers who showed a heart for Sue and the others.

Some new medications also played a role. Two were anti-anxiety meds, and two others facilitated regular sleep. A recurring challenge was that Sue did not like taking pills, and she frequently spit them out. The staff took to using some in liquid form when available and otherwise disguising the pills in other food, with modest success.

The care home is now our shared refuge. Mina and Menchie have become Sue's round-the-clock caregivers. During my regular visits with Sue, I share with her from a wide variety of helpful resources. The pictures in the 40th anniversary book prepared by our daughter Christa have been a useful link to our mutual memory of the past, and I use it to hold the faces of all our family before her. Sue smiles at the sight. I open the hymnal, and we sing together. I have a grocery bag with items to kindle remembrances — a doll, a puppet, a bag of pink curlers, a bell once used in children's choir.

Sue still loves music. She sings with me the simple children's songs she taught others: "Hallelu/Praise Ye the Lord," "Jesus Loves Me, This I Know," and our familiar morning prayer, "Father, We Thank Thee for the Night." Mina plays our favorite dance tunes: "Lost in the 50s Tonight" and "You're the Inspiration," and we stand and sway to the music. She and Menchie are the hands of God for us both. Daily we experience the truth of a song Sue used to sing: "His eye is on the sparrow, and I know He watches me."



CHAPTER TEN

The Shepherd in the Valley

I have had moments of isolation and despair in this journey. I have shed more tears in the past two years than in the rest of my years put together. Our children and I have struggled to accept this new reality. We each hold a reservoir of emotions. Irrational guilt and anger intermingle with sheer sadness.

When I feel like I'm a lost sheep, I need reminding of the Shepherd in this valley who uses such situations to probe and examine my faith and to show me His grace. "Count it all joy, my brothers, when you meet trials of various kinds, for you know that the testing of your faith produces steadfastness. And let steadfastness have its full effect, that you may be perfect and complete, lacking in nothing" (JAMES 1:2-4).

The seven years of Sue's illness have tested my faith and brought me to ask: "What is God teaching me in my trials?" I've learned to see and understand our mortality. The Benedictine monks say that we ought to hold death daily before our eyes to appreciate the *now* and make the most of the time God gives; that is, we learn to pray, "teach us to number our days" (PSALM 90:12). Alzheimer's disease relentlessly drives that lesson home. It must be faced honestly if we are to understand the preciousness of life. It is a prerequisite for taking seriously Christ's call to repentance and faith. What's more, His resurrection empowers my hope that this illness and our mortality are not the last word. That belongs to Christ, who promised, "Because I live, you also will live" (JOHN 14:19).

This disease also reminds me of the priority of relationships over possessions. Our relationship with God. And with one's family. As I watch Sue slip away from me, I realize how much of my life and sense of well-being have revolved around her and how much of my spiritual strength depended on her example, especially in my prayer life. If I were allowed to return to the past, like Emily in Thornton Wilder's play *Our Town*, what would I want to experience again? Whatever days or experiences I was given, I would hold her face in my hands and testify to her of things she no longer understands: what an incredible blessing she has been, that she has been the instrument of God's gracious care through the 53 years of our marriage. I challenge you as a reader to ask yourself, "Am I doing that *now*? Am I making the most of the relationships that are important to me?" Wilder's Emily wonders if we humans really understand how precious is the time while we are living it "every, every minute."

Douglas Groothuis writes that one lesson we caregivers need to learn as we deal with Alzheimer's disease is how to "lament without complaining." The Bible not only *permits* us to grieve but *urges* us to do it. We see such lamentation modeled in the Psalms, and we can read a whole Bible book — Lamentations — that mourns the fall of Israel and the death of thousands of people. Taking our cue from these places, we lament for ourselves, and we come alongside others and "weep with those who weep" (ROM. 12:15). At the same time, we dare not fill our prayers with gripes against God or spend our conversations playing "Ain't it awful?" for in so doing we will miss the gifts and help God sends.

Alzheimer's disease is an (often) unpleasant journey of self-discovery, especially the discovery of my weakness and sin. The daily frustration of being a caregiver has shown me with painful clarity that

I am not as loving and patient as I once professed to Sue in our college love letters. The disease has furnished a perspective from which I see clearly my desire for control. I also see with painful clarity that I am *not* in control. Instead, I am summoned to a crucifixion of my selfishness that I strenuously resist. I have been astonished how easily I am angered, how readily I utter angry vulgarities or simply scream in rage at this wretched situation. In church I have never spoken the confession more sincerely than I do now: “I, a poor, miserable sinner confess unto Thee.” Regularly, I am moved to tears at the absolution the pastor pronounces: “I forgive you all your sins.” The wondrous grace washes over me, and I realize that His death paid the particular debt of my untamed temper and harsh words.

God has made plain in a score of ways through a variety of people how He is able to surround us both with His tender care. Our children have all been a vital and unfailing source of listening and empathy. A young family in our church has taken extra time to prepare gifts for Sue in her care home — an Advent calendar, a large-print *Portals of Prayer* devotional booklet and sweet personal cards. Another family has brought me edible treats in bags again and again. My granddaughter sent me a book about living with hope. Just lately our son and his family came to sit with Sue and share words of love and songs. I receive phone calls and cards. Arms around my shoulder. And so much more.

I am hungrier than I have ever been for the restoration God has promised (ROM. 8:18-25). New heavens and new earth. Sue in her right mind again. The celestial music and heaven’s song. Seeing our Lord’s blessed face. Hearing, “well done, good and faithful servant” (MATT. 25:21). In this hope I live. Where do you anchor your hope?

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The story of Jill and Eustace did not end in that Deep Realm. Aslan’s name and his great, good magic opened the way for them to return to Overworld and see again the sun in its glory. It brought them at last to their home in England and the “healing of all harms.”

Psalm 23 tells us the same. Our journey does not end in the shadows. After the dark night comes a joyful morning. The good news is in the prepositions: “Yea, though I walk *through* the valley of shadow of death ... thou art *with* me ... I will dwell *in* the house of the Lord forever” (PSALM 23 KJV). The Shepherd guides the traveler through the shadows and through his fears. There is a going home at last.

That’s the song Sue sang at many a funeral, and I can still hear her singing it to me as I play the CD I carry in my car:

*Goin’ home, goin’ home, I’m just goin’ home,
Quiet-like, some still day, I’m just goin’ home.
It’s not far, just close by, through an open door,
Work all done, care laid by, goin’ to fear no more!
Mornin’ star lights the way, restless dream all done,
Shadows gone, break of day, real life just begun...*

In His severe mercy, God uses our human trials as His invitation to turn from the temporary and illusory things we spend so much time chasing so that we may fix our gaze on the “real life” He has waiting. For Sue. For me. For you.



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