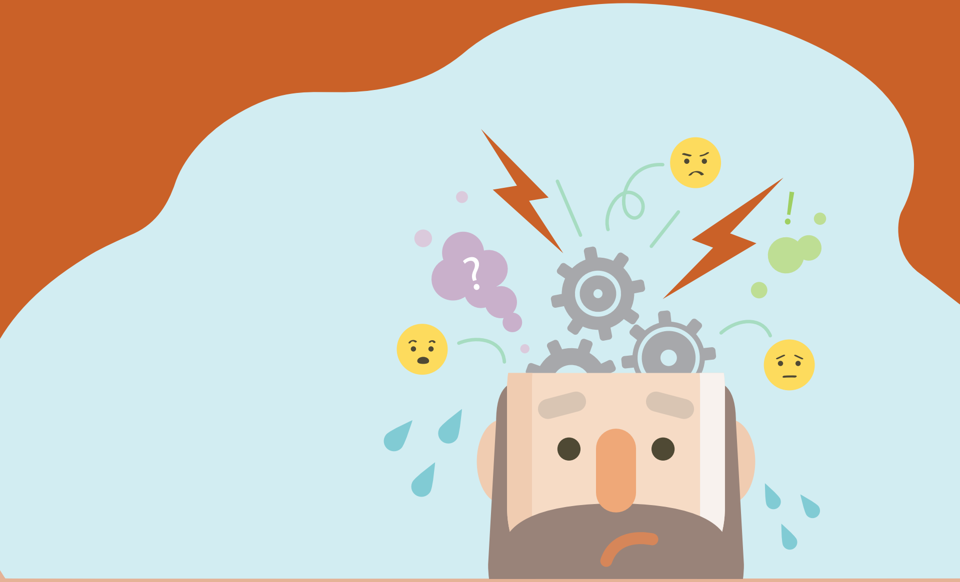
Bob's LAST MARATHON

Living the Alzheimer's Journey

Meeting the Challenges of Alzheimer's Disease

PRACTICAL GUIDE TO DEMENTIA CAREGIVING



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“A tremendous service to all
who are navigating the Alzheimer’s
journey with their loved one.”

“Thank you for sharing more
about your odyssey, Lena.”

“Your story is so touching.
Praying for a cure someday to
stop this insidious disease.”

Preface

The Alzheimer's journey is filled with challenges—some stemming from behavioral changes as the disease progresses, and others from caregivers becoming overwhelmed, burned out, or just unable to make decisions. Denial can get in the way of moving forward. How do we recognize signs of denial and how do we overcome it? How do we begin to think about the tough decisions ahead of us? What happens when we face difficult and perhaps aggressive behavior? Through the stories of caretakers and professionals, this e-book gives us ideas on how to cope and, just as important, tells us we are not alone in the problems we face.

This e-book series follows the four categories of our podcasts—Planning, Living Well, Community, and Challenges—and includes links to our podcast library.

With gratitude to our Advisory Board, family, friends old and new, and especially our guest speakers, who so generously share their personal and professional experience in the care of people with Alzheimer's disease and dementia.

Denial

Podcast Link

Lena Chow Kuhar

One winter day, Bob and I found ourselves at the local Department of Motor Vehicles in a modestly furnished office. Stainless steel desks. Filing cabinets, vinyl chairs. On the wall was a piece of Chinese art. We were speaking with a supervisor—I'll call her Ms. Chan. She was Chinese, like me. She had a kindly face. With compassion, she informed me that Bob had failed his driver proficiency test. Again.

I had met Ms. Chan briefly a year and a half before, when Bob first registered for the test. At that time, Bob was newly diagnosed, and by California law, his doctor was required to notify the DMV—which triggered the need for a retest.

That day in 2014, 18 months after Bob's diagnosis, I was still on a quest to help Bob keep his driver's license at all costs. I wanted him to drive the single mile to and from his health club. I wanted my husband, a former pilot with a perfect driving record for over 50 years, to keep a little bit of independence. I wanted to believe Bob was still basically fine.

When Bob failed his second driving test, I hired a driving instructor. I also hired a lawyer named Tim, who specialized in helping people regain their driver's licenses. It was with his help that Bob was allowed the multiple test attempts—and failures. Tim was waiting in the parking lot, ready to fight for another test if need be.

Ms. Chan gave me a look of intent, and informed me that if I insisted, she would schedule another test, but that the results would be the same—Bob would surely fail again. She said, "Perseverance may be a virtue, but now, we have to accept that this isn't going to work. Bob is not going to drive again." In my heart, I knew she was right. Something about her tone and manner—serious, touched with finality and compassion—helped me make the next decision.

I thanked her and we walked back to the car, where I then thanked Tim for his efforts, and told him I was done contesting—and we went our separate ways. Bob did not seem to fully grasp the situation. He just seemed relieved to be with me.

Ms. Chan's honesty marked a turning point in my care for Bob. I began to realize the power of the force that had robbed me of valuable time I could have spent constructively. I could have used that time exploring options to improve Bob's care. I could have been planning for the days ahead, when his condition would certainly decline. I see how irresponsible it was to pursue a goal that was dangerous not only for Bob as a driver, but also for others on the road.

Experts say that denial is common in the context of a life-changing diagnosis like Alzheimer's, and I saw it not only in myself, but also in others. I remember a couple at our first support group meeting for newly diagnosed Alzheimer's patients and families. They were very much like Bob and me in age, education, and general demeanor. I noticed the husband attending to his wife, who looked confused and agitated. When the moderator asked them to introduce themselves, the husband said, "Actually, we don't think either one of us has the disease. We're just here to check things out."

When I think about it, I was denying the seriousness of Bob's deficits for years before he was diagnosed. In 2009, three years before his diagnosis, we went to Paris, one of our favorite travel destinations. Bob was always my navigator. He might mispronounce every word, but he always knew how to get us where we needed to go. That time, though, I realized that Bob had no memory of subway stops once so familiar to him: He didn't know which way to go. Right then I knew something was wrong. But I wasn't willing or able to face it until our daughter said, "Get him tested," which I did—if only to confirm that it wasn't true. But it was.

In retrospect, there were also signs that Bob himself was aware of his deficits well before being diagnosed. After a career as an engineer, at age 69, Bob had earned a PhD in clinical psychology. But he decided that, rather than take the test for a license, he would pursue work coaching men's groups and doing crisis intervention. He never said so, but I suspect it's because he knew he would not pass it. Maybe this was his way of subconsciously intervening in his own crisis, one he wasn't willing to admit. Years later, after Bob passed away, I found folders full of articles on Alzheimer's research. I now know that he realized something was wrong, but was keeping it to himself. It saddens me to think that he harbored this fear.

Denial can take many forms, and it's easy to underestimate its devastating effects. Driven by the fear of losing autonomy, someone who is slowly but surely beginning to experience dementia may become angry or defensive when family members offer help with things as innocent as paying bills.

Or we may deny our physical limitations, which can be dangerous. I remember a man in our support group who talked about worsening back pain from supporting his wife as they walked up the stairs to their room. Everyone in the group suggested he get help, but he insisted that he was physically strong enough to handle it. Then one day they were injured falling down the stairs together. I made a mental note, and when the time came that Bob was having trouble, I asked for our home care person to stay a little later in the day—till after dinner—to help get Bob upstairs.

Reflecting on those 18 months anguishing over Bob's driver's license, I feel dismayed at the amount of energy I invested in this futile effort. Our daughter, Andrea, was aware that it was a folly; she always knew that Bob would never pass the test. But wisely, she also knew I had to play it out. Deep in denial, I was not being logical, and no amount of reason would talk me out of my goal of proving Bob was still okay. I had to come to the realization myself, but with a nudge from a woman at the DMV.

Lena Chow Kuhar

The Triadic Model: Shedding Light on Challenging Behaviors

Podcast Link

Rachel Wiley, MS, OTR/L, CDP

If you care for someone with dementia, you've probably seen the individual change over time, and start to behave in ways that can be confusing or even distressing. They might wander, wake at night, seem agitated, or act aggressively. On the other hand, they may resist engaging in activities or experience distressing beliefs. These are just a few of many examples.

As clinicians, we know how troubling these behaviors can be, and we turn to a variety of models that help us shed light on them so we can help people to cope better. All models have merits, but the approach I'm going to describe is the one I often use. It's called the Triadic Model, developed by Dr. Laura Gitlin and Dr. Mary Corcoran.

As the name implies, the Triadic Model suggests that the triggers or causes for dementia-related behaviors can be grouped into three different areas: the person with dementia, the caregiver, and the environment.

Let's look a little more closely at each, starting with the *person with dementia*. We begin by asking, what's happening within the person to possibly explain their behavior? Are they in pain or feeling uncomfortable—too hot or too cold—or experiencing medication side effects? Do they have an underlying medical condition, such as a urinary tract infection? How are they doing emotionally? Are they feeling a sense of loss of control? Are they under- or overstimulated, afraid, or confused about what to do?

Secondly, we explore the *caregiver*'s actions. We understand how difficult it can be to adjust to changes in the person with dementia. The way you always spoke with them may now inadvertently spark challenging behaviors. Some common triggers include using complex sentences or speaking quickly. Other examples might include under- or overestimating the person's capabilities, rushing them, blaming them, yelling, not keeping a consistent routine, or even not making eye contact.

Finally, we look at the *environment*. Are the rooms too dark or bright, what's the noise level, the temperature? Does the house lack stimulating activities, or is it cluttered and *over*stimulating?

Because the person with dementia can't always articulate their unease—whether it originates within themselves, from the caregiver, or from the environment—they may express it through challenging behaviors.

There's no better way to understand how the Triadic Model works, and why we are such advocates, than through example. Let's look at a common behavioral challenge, agitation. Although each person displays agitation differently, in many of my clients it often seems to arise in the afternoon and early evening—as was the case with Louise, who became agitated around 4 pm. Louise, which is not her real name, would pace around, saying, "I want to go home," and respond harshly when her family called her to dinner.

First we asked, what was going on within Louise that may have caused this behavior? She appeared confused and disoriented—she seemed to feel unsafe and insecure. It's possible she didn't recognize her family. Also, Louise typically moved her bowels after dinner, which would help reduce her agitation. It's not often discussed, but the urgency for a bowel movement is a common trigger for agitation and aggressive behaviors. It's also likely that Louise was tired after hours at adult day care.

Second, looking at the caregivers, we found that when she said she wanted to go home, they argued with her, saying, "You *are* home!" They tried to reason with her and explain why she needed to eat dinner.

Third, Louise's environment seemed overstimulating. Upon returning home from the day program, she was met with multiple family members milling around the house, making dinner, and talking, and the television on in the background. The noise and commotion likely fed Louise's agitation.

We made a number of adjustments. First, we set a toileting routine for as soon as Louise came home. We also suggested ways to reduce the stimulation: While the family made dinner, Louise rested quietly in the den, closing her eyes or listening to calm music. The caregivers also adapted their language, using comforting phrases to help Louise feel more secure, like "I know you want to go home. You're safe," and "I'm here with you."

Louise greatly benefited from these changes. We were all happy to observe a significant decrease in her agitation.

Many caregivers can relate to the problem of their loved ones wandering into the street. Which was the case with Michael (not his real name), who would wander from the home while his wife, Lisa, worked in her home office.

Let's look at what was happening within Michael. First, he might have been bored. While Lisa worked, Michael watched TV all day in his recliner. Maybe he got hungry or thirsty, or wanted to see his wife. Perhaps he needed to stretch his legs or use the bathroom. Michael would not have been able to express these needs. Also, Michael wasn't used to being sedentary: He had been a security guard monitoring buildings, which involved a good deal of walking.

Looking at the second category, the caregiver's actions, we found that Lisa's communication was not a significant trigger for Michael's wandering.

However, Michael's environment did contribute to his wandering. His recliner faced the front door, a natural trigger for wandering. There were no locks or alerts on the door to let Lisa know when Michael opened it. Also, the environment lacked stimulation, so the door was his focus.

We addressed these issues one by one. We suggested that Michael use the bathroom regularly and made sure he was well fed and hydrated. We recommended regular exercise, as well as activities besides TV. To help him feel more secure, we suggested Lisa move her office to a place where Michael could see her and she could keep an eye on him. If that wasn't possible, Lisa could employ a non-medical home care person to supervise and engage with Michael while she worked.

We offered a few strategies to address the environmental triggers. Michael's recliner could be repositioned away from the front door, which could be camouflaged with a picture, or with a canvas to make it look like a bookshelf. A remote alarm could be installed to alert Lisa when the front door opened. Other safety measures could include using GPS trackers—there are GPS watches and shoe inserts, as well as toggles that can be sewn into a jacket or tied into shoelaces.

Finally, I'm thinking of a recent client, let's call him Joe, who was being cared for by his wife, Mary. Whenever she told Joe it was time for a shower, or asked if he was ready for a shower, Joe answered with an emphatic “No.”

Looking at what was happening within Joe, we noted a few things: He felt cold, he seemed to feel a sense of loss of control, and he was afraid. But also he felt overwhelmed by having to shave and shower the same day.

Next let’s think about the caregiver. In this case it was the word “shower” and the way that Mary was presenting the activity by asking, “Joe, are you ready to shower?” that was a primary trigger for resistance. Mary had a very calm, kind tone of voice and did not rush Joe, so these were not contributing factors to resistance in this circumstance.

Lastly we can consider the physical environment. The bathroom was cold and the water usually wasn’t turned on until after Joe was in the bathroom, so it took time for the water to adjust to a comfortable warm temperature.

In Joe’s case, the strategies to address these issues were straightforward. We started by warming up the bathroom by running the hot water ahead of time. This removed the temperature barrier. This also gave Joe a cue that it was time to take a shower. Environmental cues like this can give the person with dementia a sense of control, and make them feel less resistant. We also considered Joe’s routine. Since Joe seemed overwhelmed by shaving and showering on the same day, we decided to alternate shaving and showering days to lower the level of stimulation.

By simply adjusting her phrasing to simple and generic words like “Come with me,” or “Let’s take a walk,” Mary could lead Joe to the warm shower without a struggle. The important component to consider is avoiding the trigger word or phrase; in this case, it was important for Mary to avoid the word "shower."

I hope that I've given you a sense of how the Triadic Model can be used to bring more clarity to dementia-related behaviors. By helping to identify their possible causes or triggers, this model offers a starting point for creating strategies that will, hopefully, help improve the quality of life of people with dementia and their caregivers.

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Understanding Agitation

🔈 **Podcast Link**

Judith Johanson

When I'm asked about our dementia journey, people's well-meaning first question seems to be, "Did he forget you?" or "Did he ever get aggressive, or hit you?" These are not simple questions, and they certainly do not have simple answers, but they are on everyone's mind.

My answer to the first question is that the heart never forgets, so while my name might have escaped him at times, his heart never forgot me and we were always connected.

My answer to the second question is a little more complicated.

One March afternoon, about three years after Steve's diagnosis, my father-in-law, Cliff, paid us an unexpected visit. We could tell he was upset. Standing at the front door, he said he didn't know what to do, that he couldn't get his wife to calm down. We saw Claire sitting alone in the car, staring straight ahead as if we weren't there. Claire was diagnosed with Alzheimer's four years prior to Steve's diagnosis.

I ushered Cliff into the kitchen while Steve walked with Claire through the house, looking at photos, holding hands, laughing. She was telling a detailed story about just returning from her mother-in-law Ruth's house and baking cookies. It was all very pleasant, except for the fact that Ruth had been dead for years.

When they joined us in the kitchen, Claire gave me a look I had never seen on her face before. She leaned in close and accused me of stealing her husband, yelling, "Who do you think you are to go after a married man?" Steve and I were stunned. Looking embarrassed, Cliff gave his wife a kiss on the cheek and calmed her down by reassuring her of his commitment to her.

After they left, Steve and I hugged and cried, shocked by the sudden transformation of this consummate mother and grandmother into a hostile person. I couldn't help wondering what lay ahead for Steve. As though reading my mind, Steve looked at me and said, "That will never happen to me." He assured me he could never be combative because it just wasn't his nature. What he didn't say, but was well known to both of us, was that it wasn't Claire's gentle nature either.

About a year later, we were shaken to the core seeing Claire screaming and pounding the windows of a geriatric psych unit. My heart broke for her, and for my darling husband, who had to witness his mother in this unrecognizable state while fearing it was a preview of his own future.

Over the next few years we saw only a few incidents of agitation or confusion. Little things, like snapping at the waiter apologizing for a delay in our food. Or accusing our son of wanting our car and plotting to steal our tools—this from the same man who gave his son that car, and felt privileged to have a son who often sought his counsel.

Many times over the years, Steve would ask medical professionals whether he was destined to follow in his mother's footsteps. The answers ranged from "We never know from person to person what will happen" to "Sometimes it never happens"—words that gave us solace.

But over time, Alzheimer's inevitably took possession of Steve's brain. Sometimes it would reveal itself as uncontrollable sadness, other times as delusional obsessions—wishing that he had one decent pair of pants, for example, even though he already had many. Possibly more painful were lucid moments when Steve realized all that he was losing.

Carly and Luke, our amazing children, and I did our best to cope. We'd validate his feelings and redirect his agitated thoughts. Sometimes we were able to bond over unimaginable scenarios, like when all 6 feet 2 of Steve came nose to nose with Luke and said, "Don't worry, I'm not going to hit you, but I sure as hell would like to." Through our tears, in this surreal moment, we caught each other's eye, and we found a moment of humor. At other times, the grandchildren were the best remedy we had.

A turning point came one beautiful summer afternoon. Sitting outside, Carly and I could see Steve's mood changing and guided him into the house. Walking across the kitchen supported by his two most beloved women, Steve stopped dead in his tracks, clenched his fist, turned to me and then struck out at me. Carly and I instinctively responded in disbelief, "You can NOT do that! That is NOT okay!" We got him to the sofa and looked at him, our sweet gentle husband and father, and realized it wasn't STEVE who struck out, it was the severe symptoms of his disease.

We knew this was just the beginning, and we needed to be better prepared, both emotionally and physically. One doctor helped by relating these incidents to a seizure. When a person has a seizure, they are not acting like their usual selves; their actions are disease symptoms. This really helped us feel empathy and patience, as opposed to aggravation.

A care coordinator from the Alzheimer's Association reminded me that while I was doing a great job keeping Steve safe, I needed to remember that my safety was paramount. If ever I needed to step away to protect myself, she said, then indeed I should.

With each week, Steve's symptoms became worse, and more frequent. My dearest darling would sit looking tortured, rambling on to an empty corner of the room. I recorded some of his monologues and listened to them over and over to find traces of reality. I hoped to find a real, fixable source of his agitation, so that maybe I could alleviate it.

During this time, I was in constant contact with his neurologist, Dr. Teresa Gomez-Isla. She was very careful with anti-psych medications and dosage. She reminded me that, sadly, there was no pharmacological solution for agitation.

It also was becoming clear that our once reliable methods for redirecting Steve were getting less and less effective. Sitting by the pool no longer brought him peace. But the ultimate sign that things had drastically changed came when the grandchildren could no longer snap him out of his agitated spells. Adjustments in medications helped for about four days, and then it would seem like the symptoms out-battled the higher dosage and came back with a vengeance.

Each evening around 5, I could see the veil of confusion descending. Steve would start pacing and wringing his hands. "Come on," he'd say urgently. "Let's go, they have guns and they're coming to take the kids." Even in his state of delusion, I could see the real Steve coming through in his need to protect his children.

But there were times when he saw me as someone else, and I had to protect myself against his defensive behavior. I placed a white wastebasket in each room, a safety measure to keep him at arm's length if need be. This allowed me to stay close enough to offer support, but also stay safe. And, there were times I did need to step outside and watch him through the doorway, or call my kids or a friend to help us find our way back to our baseline.

On October 21, 2017, Alzheimer's made it clear that we were no longer in control of our lives. Steve was pacing and tipping furniture over. At Dr. Teresa's urging, we took him to the ER, hoping for admission to the geriatric psych unit, where we could decide our next step.

After we had waited for hours there, Steve's hallucinations set in. The aides seemed more focused on restraining him—with force—than helping him feel more comfortable. How could it be that medical professionals didn't know how to navigate these late-stage symptoms of Alzheimer's?

After he had spent four days in the ER, four weeks in a geriatric psych unit, and four and a half months in a skilled nursing facility, I asked my darling if he was tired of all this. He didn't even open his eyes, but a tear rolled down his cheek as he nodded. I was grateful that we felt the same way—more proof that the heart never forgets.

I reminded Steve that I would be okay, and even after a thousand years together we still wouldn't have known how to say goodbye to each other, that nature had a different plan, and that it would be wise for us to respect it.

Seven days later Steve broke free from the chains of Alzheimer's, and his gentle soul found peace.

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Complacency

Podcast Link

Lena Chow Kuhar

It was late morning when I arrived at Bob's day care center, and the outdoor July 4th festivities were in full swing. It was the first time I'd visited since the Thanksgiving luncheon. I'd been so touched and thankful for the program's loving care of Bob, I returned later to deliver a cash donation. This time, I came prepared with my checkbook. There was a band, people milling around, participants seated with staff and family members—but no sign of Bob. Eventually I found Kathy, the receptionist, who somewhat sheepishly informed me that Bob was inside.

In the corner of a large empty hall at a round table that seated at least 10 people, there was Bob, sitting alone. At this point in his disease Bob was largely confined to his wheelchair, but he was as calm and good-natured as ever. So he wasn't in danger being alone for a little while, but why wasn't my very social husband enjoying the party with everyone else?

I sat down beside him, not knowing what to expect, and was soon joined by Thomas, Bob's home care aide, to share in the festivities. The table gradually filled with participants and staff, and when the waiter came for our order, Bob gleefully chose a hamburger. Curiously, the staff member across the table looked surprised. Bob devoured his burger, and after I took a few bites of my hot dog, I left Bob and Thomas to talk to Kathy.

She told me that Bob had been eating separately because of his restricted soft food diet, and when he sat with other participants, he would try to grab food from someone else's plate. I was shocked. Not so much by Bob's behavior, but what was this "restricted diet"? Kathy explained that the day care center's speech therapist had diagnosed Bob with a swallowing problem and he needed to eat only soft food. This was all news to me—there was absolutely no sign of swallowing difficulties at home. Thomas and I would have noticed because one of us was with him at every meal. In fact, because I loved how much Bob enjoyed food, I had recently made a video of him eating a meal of chicken, cherry tomatoes, and olives.

What unfolded over the next few days brought a sad and abrupt end to five years of a good experience for Bob at the day care center.

About a year before this 4th of July shock, the previous program director had left, and a new director, I'll call her Emily, took her place. Back then, I'd made a point of meeting Emily and took part in a few of her weekly support groups. She seemed like a nice enough person, but I started to notice a significant number of emails during the day, reporting on something she found online or reminding us of upcoming dates and events. It crossed my mind that Emily was spending more time surfing the Internet than overseeing the center's participants. At the same time, the customary updates on Bob's status came to an end. I didn't pay much attention because I knew Bob's care team, and, based on how settled he seemed at home, I felt that he was doing well at day care, too.

Over the next few days I mobilized my research skills. I began by meeting with Bob's primary care physician, who immediately ordered a swallowing test. I spoke with Sue, the new program director who had replaced Emily recently, and Kathy, who saw Bob every day. I even questioned Jack, the driver who took Bob to and from day care five days a week. I also asked our care manager, Stephne, who had been guiding me about Bob's care for several years, to meet with the care center staff and observe Bob over the course of a day at the center.

My findings were confusing and distressing.

The first step was the swallowing test, which was with a speech therapist at our health care system, as requested by Bob's primary care physician. It was a bit of a cliffhanger. Bob wouldn't eat the food offered for the test. After a few tries, I told the speech therapist how much Bob loved apples, at which point the speech therapist broke into a smile and "donated" the apple from his own lunch. Sure enough, it worked. And, as Thomas and I suspected, there was nothing wrong with Bob's swallowing.

At the day care center, word had it that Bob was uncooperative. Plus, with his declining mobility, Bob now required two people instead of one to help him with even basic routines like going to the bathroom. Overall, Bob had become more of a challenge.

This was confirmed by Kathy and the new director, Sue. I had known Sue through a mutual friend, and was relieved to be able to talk to her. Sue was extremely kind and agreed the center was remiss in neglecting to inform me about the speech therapist's assessment. But both she and Kathy were clear: They wanted to reduce Bob's hours and ultimately phase out his attendance.

In turn, I was clear with them. I could understand an error in diagnosis—these things happen in the best of institutions—but I held the center responsible for not notifying me. If the problem was serious enough to change Bob's diet, shouldn't we have made the changes at home as well? Couldn't this have put Bob's health or life at risk?

Before leaving, I agreed to the reduced schedule.

The next day, I informed the day care center that Bob would not be returning. I saw no reason to prolong a difficult situation. To fill in Bob's schedule, I modified his routines as best I could. Jack took Bob out for a drive twice a week. I added more art therapy sessions and exercise outings with his trainer. Bob spent more time with Thomas at nearby nature preserves, feeding ducks and enjoying the beautiful scenery. Bob seemed glad to be home.

Sue and Kathy would contact me every so often to check in on Bob. I never heard from the speech therapist who gave Bob the diagnosis. I thought about reporting the incident to state regulators, but decided my energy was better spent caring for Bob.

Ultimately, I place the blame on myself, and I learned an important lesson. I couldn't take anything for granted. Over the course of five years with the day care center, an experience that had been mostly wonderful, I never had reason to believe he was not receiving good care. And because Bob seemed settled at home, I never suspected a problem during the day. The slip on my part was not acting on the most important cue: I had stopped getting reports from the director. This oversight had likely led to some discomfort, if not distress, for Bob during his last few weeks at the center. I had grown complacent. Luckily I caught it before more damage was done.

But happily Bob thrived at home—and ate the food he loved to the very end. In my mind's eye, I can see Bob eating a peach the night before he passed away.

Lena Chow Kuhar

Feeling Sure

🔊 **Podcast Link**

Katherine Diane Brandt

In the summer of 2011, my 2-year-old son Noah and my 31-year-old husband Mike were the same. What I mean is, they had more in common than most fathers and sons. They were entertained by many of the same things, they were bad at following directions, they both showed erratic behavior. All typical for a toddler—not so much for a grown man, unless you have Mike's condition: frontotemporal dementia or FTD. So while Mike and Noah were on a similar cognitive level, their needs were very different.

I was the key caregiver for both—as well as for my father, who had early-onset Alzheimer's.

With the recent passing of my mother, I felt very alone and overwhelmed with the responsibility of making so many health care decisions and choices for my family.

When Mike's condition deteriorated the year before, I made the difficult decision to move him to a neuro-rehabilitation center nine miles away. I was aware this meant less time for Noah to know his father—and for Mike to enjoy his son. So when the care manager asked about my goals for Mike's care, I immediately answered, "Family time."

We set the stage for visits by following a routine: a short activity, a snack, a photo. Noah and I would arrive with bubbles, hula hoops, or balls and wait for Mike and his therapist outside the locked unit door. I would entice both to the courtyard with a snack.

Snacks were important. Mike and Noah had to have the same, otherwise Mike would want to take what Noah had, and vice versa. There was always a staff person with us to give both Mike and Noah one-to-one support and help take the required family photo.

It sounds organized, but felt more like a bizarre circus. Mike quickly circling the brick courtyard path. Noah running back and forth, pushing the handicap button to open the courtyard door. Noah hiding in the bushes and screaming “Boo!” at Mike. Mike and Noah laughing.

I didn’t worry about time; a 15-minute visit one day could be a 40-minute visit the next. I looked for special moments.

Sometimes when Mike was on one of his walks, Noah would reach up and take his hand. They would stroll, not talking, for a lap or two. One time, in fun, Noah whacked Mike on the head with a stick. Just as I was about to reprimand Noah, Mike burst out with a huge belly laugh, which made Noah giggle uncontrollably. Their shared joy was so clear, I had to let it go.

As summer turned to fall, I began to notice changes. Noah was mastering the art of scooping guacamole onto tortilla chips—his favorite snack—as Mike started to lose that skill. Noah showed interest in potty training while Mike’s staff and I discussed the need for adult diapers both night and day. Noah became a sturdy, steady runner as we started worrying about Mike’s balance and risk for falls.

I had a pit in my stomach before each family visit. I found it harder and harder to get Mike to focus on Noah—who seemed less and less enthusiastic about our family visits. Once when I was buckling Noah into his car seat before seeing Mike, he said to me, “Daddy scary.”

That was a turning point.

We were reaching a new mile marker in the FTD journey and with it, a new decision.

How many more visits would my son have with his father? I felt an overwhelming urge to protect Noah. I knew his memories of Mike would be limited and I didn't want them to be negative or scary.

And, just as fiercely, I wanted to protect Mike. He had wanted to be a dad for so long and he loved Noah so completely. I wanted to preserve Mike's dignity and the positive feelings between him and Noah.

In the end, I would rather Noah have just a few happy memories than many sad ones—but was this the right decision?

This moment was an example of isolation in my caregiving experience. With my mother recently passed and my father in the early stages of Alzheimer's, I had no parents to turn to for advice. Certainly, none of the other moms in my Mommy & Me classes were grappling with this issue. I felt judged for bringing Noah into the neuro-rehab center, and equally guilty for thinking about keeping him out. I could only share my thoughts with a select few. Virtually alone and unsure of myself, I wondered whether I was making the right decision.

I stretched the time between visits to days and weeks, finally planning for a dual birthday party in March. Noah would be three, Mike thirty-two. We had an ice cream cake and presents. There were balloons and streamers. A photographer whom I had met through the FTD support group donated her time to take family pictures of us. It felt like the end of something. A celebration that was a goodbye.

Six weeks later, Mike was in a wheelchair full time. Falling frequently and unable to engage the motor skills to stand up, he was safer strapped into a chair. I didn't want Noah to see him that way. The time from one visit to the next got longer.

Then one day in the car, Noah said to me, "I just want to say hi to Daddy." It was a request I couldn't deny. So I made a plan with Mike's favorite aide to have Mike sitting at a courtyard table when Noah arrived, the wheelchair hidden out of sight. I brought ice cream from Friendly's. Noah fed himself while the aide fed Mike. Noah ran around the courtyard and I could see Mike watching him. Noah sang songs for our applause and laughed when I bestowed eyelash butterfly kisses on Mike's cheeks. We took a family photo. As Noah and I walked out of the courtyard, Mike stayed seated. Noah blew him kisses with his chubby 3-year-old hand and yelled a quick "Bye, Daddy! Love you!" As we walked down the hall to the exit, I knew it was the last visit. I felt sure. I just didn't know if I felt right.

Less than a year later, a week after Mike's funeral, and Noah's 4-year-old voice piped up from the backseat: "Mom? Can Memere talk in heaven?" I wondered why Noah was asking about my mom, who had passed away three years before. "Yes, of course Memere can talk in heaven." Noah was quiet for a few moments, and then said, "Mom? Can Daddy laugh in heaven?" That got my attention. "Noah, are you remembering that Daddy didn't talk, but that Daddy laughed?" Noah was quick to respond, "Yeah, Daddy not talk, but Daddy laugh a lot."

There it was.

After not seeing Mike for nine months, Noah had a positive memory of his father. Thinking of him laughing. Laughing in heaven. That moment was a gift for me. A gift for Mike.

To know that locked inside our son's heart there was a memory of joy and happiness gave me hope. Hope that Noah could grow up with memories he would want to keep. Because I had protected his heart and his father's dignity. It finally felt like the right choice.

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Moving Forward

Podcast Link

Katherine Diane Brandt

On the way to work one sunny Tuesday morning, I suddenly felt my steering pull sharply to the left and slowed into the breakdown lane—sure enough, my rear tire was flat. My call to my husband, Mike, went to voicemail, so I left a message telling him where I was, and that I would call my dad next. Dad answered on the second ring, and seconds later I could hear him heading toward the door.

Mike arrived a few minutes later, greeting me with a kiss, and was examining the tire when Dad pulled up. Just as they opened the trunk for the spare, a state trooper arrived. While Mike talked to the officer, Dad gave me a kiss on the cheek, put his car keys in my hand, and said, “Go ahead, Kate, we’ll take it from here.”

Dad and Mike. How lucky to have their protection when my life swerved out of control. I felt my present and my future would always be secure with them in my life.

The next few years only reinforced my feeling of confidence and good fortune. As our new marriage grew, Mike proved a caring and attentive partner. Even more than his sweet gestures of affection, it was his concern for our future that made me fall deeper in love. We took turns going to graduate school, with Mike encouraging me to go first while he took a second job. Our degrees turned into jobs, and jobs into careers. We bought a three-bedroom Cape in a lake community, and just weeks before our fifth wedding anniversary, I found out I was pregnant with our son, Noah. Our love propelled us forward.

My parents were thrilled at the prospect of their first grandchild. Mom talked excitedly about maternity clothes, ultrasounds, and plans for an epic baby shower. Dad regaled Mike with stories of my infant companionship during late-night Bruins and Celtics games. He loved reminiscing about special times together, like taking my sister and me on secret after-school adventures for doughnuts or ice cream. Both Mom and Dad looked forward to replaying many of those happy memories with the next generation.

With happy anticipation, I steadied myself for the changes that motherhood would bring. As I prepared myself for a year of firsts, I didn't realize that I was embarking on a season of so many lasts.

The first signs were subtle. Mike became more and more withdrawn. He started having trouble at work. He rarely wanted to talk. His behavior became unpredictable.

At the same time, Dad got increasingly forgetful and agitated. One night, he got lost driving to my sister's for dinner. Another time, he dropped Mom off at the bank while he ran errands, and forgot to pick her up.

In September of 2008, I accompanied Mike to his annual physical. "My husband is acting so weird," I told the doctor—and bluntly asked, "Does he have a brain tumor?" She was just the first doctor to misdiagnose him. Five months and eight medical and mental health professionals later, Mike was finally accurately diagnosed with FTD. Frontotemporal degeneration—a progressive neurological disorder that causes dementia. With Alzheimer's disease, memory loss is often the first troubling symptom, but those with FTD may exhibit socially inappropriate behaviors, personality changes such as impulsivity or apathy, and even difficulties in communication. This can make it incredibly hard to diagnose. In many ways, we were lucky to receive a clear diagnosis, devastating as it was.

Mike and I were 29. Noah was 10 months old.

It turned out that Mike's diagnosis was just the first storm in a season of loss in our lives.

Just four days after Mike's terminal diagnosis, my sister called with the devastating news that our mother had suffered a heart attack and died. She was 58 years old.

As expected, I felt profound loss and grief at my mom's passing, but her death also carried an added complication. Seventeen days later, Dad's doctors confirmed his diagnosis of Alzheimer's disease. He was 59.

Between Mike, Dad, and Noah, my role as caregiver was firmly established. The title might have been the same, but the job descriptions were not. As caregiver for Dad and Mike, I had to clear different logistical hurdles and become an expert in different fields.

Navigating finances and legal paperwork for Mike was fairly seamless: I had access to all of our accounts because our finances were combined. We lived together and shared household responsibilities, which helped my learning curve as I leaned into the tasks that Mike had always managed.

In sharp contrast, I had to become a detective to uncover the state of my parents' finances. Between my mother's sudden passing and Dad's cognitive impairment, I found myself on endless phone calls with credit card and bank representatives. I spent countless hours digging through my parents' filing cabinets. Mike and I had digitized our finances, using online banking and auto-pay services. My parents, though, were still paper-based. I had to reorient myself to the charms of paper checks and mailed bills. Eventually, I hired an accountant and an elder law attorney to help.

Each couple's financial situation is unique—but the devastating impact of young-onset dementia is a common thread for affected families. A 2017 article in the medical journal *Neurology* reported that the total annual per-patient cost of care for an individual living with FTD is nearly twice that of Alzheimer's disease—due in part to the younger age of disease onset. When dementia strikes a younger person, they're often still working and paying a mortgage, and may even be raising children. The inability to work, paired with the high cost of care, puts financial burdens on families that can have a lifelong impact for the family members who are left behind to pick up the pieces.

With such high care needs for Mike, Dad, and Noah, I had to make a choice: I decided to leave my career to be a full-time caregiver. Noah and I moved in with Dad, and I found a compassionate care team at a local skilled nursing facility to care for Mike.

Suddenly, my present life was redefined by caregiving, while dementia was reshaping my future.

It was a future where Mike seemed suddenly absent. He seemed to regress more and more with each visit to the nursing home. He lost the ability to speak and to write. It was getting harder and harder to connect. I realized I was grieving the loss of my husband and our future before he was even gone. There were so many things left undone.

My father's trajectory seemed much slower. While his memory for our daily routine slipped away, his recollections of our family life and his role as my father remained solid. He and

Noah enjoyed afternoons at the park and trips to the aquarium. I was the keeper of memories. Reminiscing with Dad was an activity we could share, solidifying our bond as father and daughter, which helped keep us steady for the unchartered waters ahead.

My grief over Dad's prognosis didn't inflict the same painful wounds I felt while watching the Mike I knew disappear. My grief over Dad's dementia was like intermittent rainstorms, with sunshine occasionally peeking through the clouds. The grief I carried for Mike felt like an oppressive dark cloud, a relentless hurricane that left destruction and devastation at every turn.

While I wanted badly for my parents to be part of my future, I knew it wasn't a given—it's natural for parents to pass away before their children. I also feel a bittersweet beauty in the reciprocal nature of care between me and Dad over time: I feel good about being his caregiver—it's my opportunity to thank him for all of his love and care over the years.

But, with Mike, I had expectations for so many tomorrows. While I'm proud I fulfilled my vows to Mike—to love him in sickness and in health—I can't help feeling cheated. FTD was the mistress in our marital bed. She broke our bond. Ended our union too early. And stole not just our present but our future. My grief over Mike is still shot through with bolts of anger. But, I can't let FTD have the final word. Mike would want me to go forward.

It has been almost nine years since Mike passed away. I have gone back to work, and Noah has grown into a middle schooler. My dad is living well in an assisted living memory care program. People ask me how I managed to "move on" and be so resilient. Moving on has always felt like setting something down and never looking back. But, for me, the past is always present. It's through my memories of the past that I build new memories for our family love story today. Noah and I make pizza on the stone that Mike and I received for our wedding shower. Noah's Christmas stocking is stitched from the blazer Mike wore to our college semi-formal. We reminisce with Dad about my childhood trips for doughnuts and ice cream while driving Noah for double chocolate doughnuts with sprinkles. We are all moving forward on a tide of swift and irrevocable change, learning to ride new waves, together.

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Bob's LAST MARATHON

Living the Alzheimer's Journey

Bob and Lena began their life together as long-distance runners. But they weren't prepared for the long, unmapped journey that began in 2012 with Bob's diagnosis of mixed dementia (vascular dementia and Alzheimer's disease). Even as a professional in health care communications, Lena was overwhelmed by the issues she faced. It took time to connect with caring professionals who helped her to map a path for giving Bob the best possible quality of life while caring for herself. Today, she wants others to benefit from her experience.

Like many of her fellow caregivers, Lena feels a calling to give back by helping others as they reach the common Alzheimer's milestones—the shock of diagnosis, transitioning from denial to acceptance, keeping pace with the relentless changes, and passing the final milestone. Lena has been there. While affirming our listeners' loss, confusion, and grief, *Bob's Last Marathon* will hopefully be a source of practical guidance, comfort, and encouragement in living the Alzheimer's journey.

"So much sound advice, wisdom about living life for anyone, and love—with an emphasis on love as a verb."

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