Bob's LAST MARATHON

Living the
Alzheimer's
Journey

Discovering Your Alzheimer's Community

PRACTICAL GUIDE TO DEMENTIA CAREGIVING

A PUBLICATION OF BOB'S LAST MARATHON FOUNDATION

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“I know your work is going to help many—even those of us who are not currently dealing with dementia.”

“This was not an easy one to write and record, but ultimately, if it can be helpful to anyone, then I’m happy to share our experiences on our journey.”

“Thank you for reminding us of the beauty of life.”

Preface

Whom can we turn to when we need help? What are community resources we should know about? What can we expect from our family? Our friends? What roles can support groups play in our caregiving? Sometimes it comes down to expectations—knowing what we can expect and setting ourselves up for a mutually rewarding experience. At other times, digging deep into ourselves to look for ways to give back can be rich and fulfilling. A good example is participating in clinical trials—donating important data we can give, as healthy individuals or as someone with Alzheimer's disease or other dementia—to advance science and pave the way to better understanding of the disease and ultimately a cure.

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.

Family

🔊 Podcast Link

Lena Chow Kuhar

People often move to California for the beautiful weather. It's usually a comfort, but on the day we received Bob's diagnosis of dementia, it felt like the opposite. As we stumbled out of the neuropsychologist's office, the sun glared with the shock we were feeling. It was the final blow after a punishing meeting with the young doctor who was charged with delivering the news. Unaware of her poor bedside manner, she went down the long list of test results repeating the same words: "profoundly impaired, profoundly impaired" over and over again. It felt like a tirade rather than a diagnosis, leaving us not just saddened, but as though we'd been handed a severe sentence for an unknown misdeed.

I can't remember ever feeling more grateful for the warmth of our family. My first call was to our daughter, Andrea, herself a physician, who had been worried about Bob for some time. As much as I wanted to speak with all four of Bob's children, I needed time to collect myself, so I asked Chris to share the news with his brother, Mike, and two sisters, Liz and Kim. The diagnosis did not surprise anyone—Bob hadn't been himself for some time. But they were all concerned, not just for Bob, but for me. I was touched that each and every one of them asked how this might affect my life and well-being. We quickly agreed that we all needed to spend more time together to enjoy each other's company while we could. And the rest of that summer was filled with visits and travel—creating joyous moments for Bob, and great memories for our family.

During the years of Bob's illness, well-meaning friends often asked whether family was giving me the support I needed. We are a large, blended family—emotionally close but far in miles. Given their distance, their own families, and busy work schedules, I realized quickly that expecting day-to-day support from family was not only impractical but unfair—I would need other resources to help me care for Bob as his function declined.

But the children did come through in meaningful ways that brought happiness to us both, and relief for me. Chris, who lived an hour away in Santa Cruz, continued his weekly lunches with Bob for several years and cheerfully offered to take on some of Bob's tasks as handyman around the house. And for as long as Bob could function well enough, Chris would also stay overnight while I traveled.

But sometimes the reality of Bob's illness, and our ability to handle it, was hard to measure and we got in over our heads. This was especially true during the early years when we were still trying to accept his disease and absorb what it really meant, before I had a caregiving routine in place. That first summer after his diagnosis, Bob and I traveled to Southern California to visit his oldest son, Mike, and his wife, Linda. I left Bob with them for a few days. From the smiling faces in all the pictures and by everyone's account, they had a great time. But appearances can be deceiving. A few months later, when I asked Mike if Bob could stay with them again, it surprised me when he politely changed the subject.

Not long after, Mike came to our home for a visit. One morning, I left Bob and Mike at the breakfast table while I ran a short errand. When I returned, Mike was in the guest bedroom and Bob was nowhere to be found. I alerted the neighbors, one of whom was a policeman, and we frantically searched until someone found him sitting, quietly and inexplicably, in the driver's seat of our next-door neighbor's car. I didn't understand how Mike could have left Bob alone, but came to realize it was his apprehension. It was difficult for Mike. How could he connect with a father who no longer shared his interest in boats and woodworking, who wasn't responding to his attempts at conversation, who was awkward in his every movement? No, Mike was not negligent. He had retreated to another room out of fear. I realized that over time, Bob's ongoing decline, especially around feeding and hygiene, would raise even more barriers to his relationship with his children. It was up to me, sometimes with the help of a home care person, to set the stage for visits that were filled with joy, not fear.

One of the gifts of family was the innocence and wholehearted acceptance of young children. To our grandchildren, Bob was Grandpa Bob. No more. No less. He smiled when they sang, danced, drew pictures, or just talked to him. They expected nothing more, nothing less, even in Bob's somewhat advanced stages of dementia. After learning that her Grandpa Bob had been a scuba diver, our 8-year-old granddaughter, Natalie, drew a picture of him in scuba gear underwater. I'll always cherish the moment she showed him the picture and how he responded simply, and with a smile, "Scuba."

This is just one example of how support from family can take so many forms. I also have fond memories of Bob getting into a pickup truck with his daughter Kim, a forest ranger, and roaring off into the beautiful California foothills. Bob grabbing the goodies from our grandchildren's Easter basket—Natalie and Peter being the expert egg hunters. Bob applauding another granddaughter, Tessa, at her violin recital. Bob and Liz, his oldest daughter, sitting together quietly, holding hands and just enjoying each other's company.

Family takes on new meaning in times of trials and deep sorrow. As Bob's physical health began to fail, visits came more often, sometimes for emotional support and other times to share the responsibility of difficult decisions, from hospitalization to hospice. In the days leading up to Bob's memorial service, Chris and Andrea came together and put together the most beautiful tributes, a true gift to Bob, and to me.

When I first began reflecting on the role of family in dementia care, my intention was to help my fellow caregivers set realistic expectations about what their family could or could not do—to help them figure out what kind of help family members could realistically provide. This, of course, depends on the family. Perhaps the more important goal is finding ways to encourage family members to step up and step in, within their abilities. It's not so much about support in day-to-day living and the chores of caregiving. It's more about spending quality time with the one we all love, honoring the best in him or her, and creating beautiful memories we'll treasure for the rest of our lives.

Lena Chow Kuhar

Clinical Trials:
An Inside Story

🔊 **Podcast Link**

Judith Johanson

My husband, Steve, and I liked to say that we hit the lottery of love when we met each other. And our love rewarded us with blessings that we embraced with joy and gratitude: two children, a home, careers that we enjoyed, a life rich in activities, the gift of our children finding wonderful partners, and, eventually, best of all, grandchildren. They were the promise that our love, DNA, and stories would continue!

To me, Steve's goodness was the source of our bounty. Always with a smile on his face, Steve had a way of making anything seem possible. He was known for his kind and giving nature, the person people turned to for a listening ear or help with a construction project. He was a voracious reader. He loved hiking and sailing, activities he so looked forward to sharing with our grandchildren as they grew older. I also knew he would pass on his values, teaching them, just as he taught their parents, that love, honesty, and kindness were their truest, most trusted compass in life. Through his actions and words, Steve showed us that giving was a gift in itself, much more satisfying than receiving.

Can you tell he was my everything?

But everything began to change in 2011. As we watched Steve's beautiful mother struggle through her fourth year of Alzheimer's disease, Steve began grappling with his own cognitive issues. He would often call to tell me the bank password didn't work, or that he'd lost his keys once again. I'd run to his office to help, only to find them in his pocket.

These were just a few signs that something was wrong. But the pivotal moment came in May 2011, when Steve received a poor performance review for his job as Construction Project Manager for the Special Projects Division at Northeastern University. It was so unlike the highly competent person who handled huge projects and budgets. It was time to find out what was really going on. Five months of testing led to the diagnosis of younger-onset Alzheimer's, just a month shy of his 59th birthday, and the beginning of the end of his 15-year career at Northeastern University.

Upon hearing the diagnosis, Steve cried, and his first thought was of our grandchildren. "I wanted to watch them grow up and play baseball," he said. But soon, in his ever-optimistic way, Steve decided that we could be happy or sad, but the fact that we had so much love was reason enough to smile every day.

We both loved this Cheryl Strayed quote: "You don't have a right to the cards you believe you should have been dealt. You have an obligation to play the hell out of the ones you're holding ..."

Steve and I resolved that we wouldn't measure our remaining years in quantity, but in how we filled them. So we dug in, held each other's hands tighter, and began walking this new road with the diagnosis strapped on like a backpack.

We found educational and socialization programs at the Alzheimer's Association. We advocated on state and federal levels for funding for research, reducing stigma, and education for caregivers and society as a whole.

Given Steve's nature, it was no surprise he wanted to invest our greatest asset in Alzheimer's research—himself—by joining a clinical trial to test out drugs under investigation.

I was far less enthusiastic. If he was in the group receiving an active drug, I would worry about side effects. And even the possibility of receiving a placebo, and missing out on any benefits of a new drug, would be tough to accept. But it was Steve's call.

Unfortunately, his particular profile didn't match the entry requirements for clinical drug trials at that time. We would have to wait for one to open up. While we were waiting, Mass General asked us to join the Memory Study, a different type of trial called a longitudinal cohort study that does not test drugs, but gathers data by following people over a long period of time. This non-drug study was a soft entry into the world of clinical research.

The Memory Study required that Steve go through a battery of tests once a year, including brain imaging, in-depth interviews of both of us, and analysis of both blood and cerebrospinal fluid. The ultimate hope was that people would add to this data by donating their brains to research.

When asked at his first visit to consider a future brain donation, Steve said, "That's a no-brainer, take it!" He and the doctor had a good laugh—I could already see the emotional benefit of being in this study! And the positive feelings continued: Steve truly enjoyed his visits, even the intensive brain imaging studies. While he would not be around to teach his grandchildren to sail, he would leave an important legacy for them: Giving of himself, Steve would contribute to research far beyond his time on earth.

We made the most of our visits, which became opportunities to meet with brilliant minds, compassionate clinicians, and energetic young research assistants, and to feel like we were part of a valuable team working toward a cure. And we would make a day of it, celebrating with lunch or dinner in town.

The appointments also gave us another chance to discuss what was going on with Steve, beyond the biannual visits with his neurologist. Alzheimer's symptoms can feel subjective, and it gave me great comfort to have a sounding board to confirm that I wasn't imagining the changes I saw in Steve. We felt closely watched, in a good way.

Steve and I arrived at each visit with the hope of hearing that the perfect clinical trial for Steve had just opened up. It took several years, but finally a drug trial opened up. The NOBLE Trial was an 18-month double-blind study; in other words, neither the participants nor doctors know who is receiving which treatment. In the end, we did find out that Steve had been taking the higher drug dose.

We looked at the study as our job, and it wasn't always easy. The parking garage was small and we would have to drive in circles to find a spot, which would result in Steve throwing up from motion sickness, but still he persevered.

After our first day, we picked our grandsons up from school. Steve told them how happy he was to have been chosen for the trial. Five-year-old Nathan asked why Gramps would want to be in the trial and what it meant. Steve explained that people were working hard to make sure that others in the future wouldn't get Alzheimer's. Nathan then asked, "Gramps, will it make you get better?" Steve answered him honestly. He said, "No, it won't make me get better, but we don't always do things for ourselves, sometimes we do them for the good of others."

The lesson we had never dreamt of teaching turned out to be far more valuable than the ones we *had* hoped to share.

Steve's trial ended in November of 2016. The drug had not provided enough positive outcomes to justify continuing. We entered the study knowing this was a possibility, and with the belief that each “no” would eventually lead to a “yes.”

Alzheimer’s continued to deliver on its promised symptoms and steady decline, and my dearest darling broke free of the chains of this disease on April 2, 2018. Steve’s wishes were fulfilled and his brain was donated to the Mass Alzheimer’s Disease Research Center at Mass General Hospital.

I proudly proclaim that Steve left his brain to Mass General, and his heart to me. I am blessed to keep them together in my work.

Judith Johanson

MADRC Longitudinal Cohort Coordinator
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Massachusetts/New Hampshire chapter
Alzheimer’s Association
www.madrc.org

Friends

🔊 Podcast Link

Lena Chow Kuhar

Two months after Bob's passing, I attended an annual conference for professionals in my industry and met up with a colleague who had reached out about working with me on a project. Over the years, Arlene, which is not her real name, had become more than just a business acquaintance—I considered her a friend. Since we hadn't seen each other for a few years, I began by letting her know about Bob's disease and recent passing. Her first response was, "Did he still know you?" I was stunned and flustered, and I felt hurt—though I didn't know exactly why at the time. My answer was something like, "Why does it matter now?" and the rest of our meeting was awkward, ending on a somber and strained note. I never saw Arlene again.

What *was* it about questions like "Did he still know you?" and "Does he know your name?" Why did they bother me so much? Over the years of caring for Bob, why did they stand out as the most hurtful comments from friends?

It wasn't until a year after his passing that I got a hint. I realized how much I cherished Bob's recognition of me. It was a sign of our connection as a couple—one of the very few traces of our bond that endured the cruel years of his decline. Bob lost his ability to get around the house on his own; he lost his hygiene, his grooming, his handling of eating utensils, and his ability to participate in conversations. But he didn't lose his connection with me. Bob still *knew me,* and gazed at me with great affection whenever I was in the room. And, somehow, he knew my name to the end. I clung to this great gift as a source of comfort, a remnant of our relationship as a couple. And for someone to question it felt like they were doubting the existence of the thing that was most precious to me, and perhaps they were reflecting my own doubts and fears. Of course, how could Arlene have known this—and so much about my life—especially when I didn't or couldn't share it?

Looking back, I can see how challenging it is to be a friend of people living with Alzheimer's disease. Sharing social activities like drinks and meals goes by the wayside when your loved one loses the ability to eat or converse. Hosting friends at your home in a relaxed way becomes nearly impossible when dealing with verbal repetitions or attending to bathroom issues. Understanding this helped me accept that even the best-intentioned, most thoughtful friends could not give me the support I needed unless they knew what I was going through.

There were exceptions. Somehow, our closer, more sensitive friends knew what I needed without clues from me. Knowing me, they understood how much I valued getting together with friends and treasured those remnants of normalcy. Some would host dinners at their homes, moving meals outdoors, where cleaning up after a messy meal was less of a problem. When Bob's mobility declined, my friends John and Susan brought cooked meals to our home to share. Problem solved! I will forever be grateful to proactive and sensitive friends like them.

But knowing what I know now, I realize I could have done a better job letting my friends know how they could help me. They needed a little guidance from me, which sometimes meant just letting them in on my challenges, and giving them *a chance* to be more sensitive.

I remember meeting my close friend Winnie for a drink on the patio of Il Fornaio in Palo Alto, a regular check-in—just the two of us. I was looking forward to some relaxing small talk. Instead, Winnie said she had great news, and launched into a story about a doctor who was touting a type of Mediterranean diet that might improve memory, and wouldn't it be great to put Bob on this diet? My indifference was obvious, and she became insistent: "You have to listen," she said, "the doctor on the radio was very adamant about this diet." This went on for about 15 to 20 minutes until she finally said, "Okay. I remember you are a stubborn person. I just wish you'd be more open to new ideas," and changed the subject.

What I didn't tell Winnie was that right before meeting her I had picked up a box of adult diapers for the very first time in my life—which left me filled with emotions. I was grieving the loss of the good old days when Bob took good care of me in so many ways, and pondering what lay ahead. I felt terrible that Bob had to endure the humiliation; he was aware of the changes in himself but couldn't control them. I also felt sorry for myself. Why couldn't my husband be normal?

Instead of sharing these emotions, I blamed my friend—one of the kindest people I've ever known—for not giving me a chance to vent. Now, I realize that she would have readily listened if I had only said, "Look. I just bought adult diapers for Bob for the first time."

Sometimes, I needed to vent. But sometimes I just wasn't ready to pour out my emotions, and I was protecting myself by not doing so.

I was often on the receiving end of difficult, emotionally charged questions, comments, and suggestions relating to Bob's illness. It wasn't unusual for well-meaning friends to go down a checklist, like some intake process at a clinic. "Does he sleep through the night?" "Does he have sundowning?" "Does he wander?" "Can he feed himself?" Over time, I learned that I wasn't obliged to indulge their curiosity. I became skilled at giving straightforward yes-no responses, in a matter-of-fact way. And for those questions that touched my inner insecurity the most—"Does he still know you?" or "Does he know your name?"—I finally learned to say, "Yes, he does. And I feel very fortunate." In this way, I comforted myself while avoiding more anguish.

Because I am professionally involved in health care, many of my friends are, too. As a result, I often received unwelcome advice in the form of articles from medical journals about the latest developments in Alzheimer's disease. Inevitably, these articles were reporting on *early success* in the laboratory. Knowing that these still-unproven treatments were many years away from being available to the public, and not relevant to Bob, I would just ignore them. Occasionally, someone might ask what I thought about the articles and, in the case of one friend, offer to introduce me to the researchers. I explained that Bob already had a doctor whom I trusted, and that these developments, while exciting for the future, were not in our reach.

I could hardly say that friends were uncaring when their first questions were usually about Bob. "How is he doing?" "Is he sleeping okay?" "Is he eating well?" Selfishly, though, I wanted my friends to ask about me—first—"How are you holding up?" "Are you getting the help you need?" "Are you able to find time for yourself?" And the critical question from only a very small minority, "Is there anything I can do?" I never found a way to let friends know how much I needed this.

The reality, though, is that friends who ask questions—any question—are at least opening the door to listening. One way or another, my good friends, children, and stepchildren did find their way to support me by listening and empathizing. Words like "I'm so happy for you" or "I'm so sorry about that" went a long way toward showing they cared and maybe opening a conversation—whereas talking *at* me with phrases like "If I were you I would …" was a sure way to stop a conversation short.

On my part, I've learned that it's on me to be aware of my feelings so I can set realistic expectations from friends. It's also up to me to gently direct the conversation to meet my needs at the time—whether it's with a simple response that doesn't burden me emotionally, or by being honest about what I'm going through, which opens the way for good friends to help in whatever way they can.

Lena Chow Kuhar

Socializing

🔈 Podcast Link

Lena Chow Kuhar

I remember the last dinner party at our home, not long before Bob passed away. I even remember the menu—roasted leg of lamb, rice pilaf, and salad that we prepared as a group together. Bob was not with us. But after we finished the main course and moved to the living room, Bob arrived with his caregiver Thomas, who, at my request, had taken Bob to a movie and dinner at a nearby restaurant. When Bob saw our friends in the room, he broke into a big smile, squeezed my hand, and settled into his chair by the fireplace as I brought out dessert—a blueberry pie, one of his favorites. Even though Bob wasn't speaking much anymore, I could tell how much he enjoyed being the guest star of our party and being with us as we chatted away.

The dinner party went just as I had hoped. It was my new plan, to give Bob and our friends time together, while freeing myself from the anxiety of taking care of him at the dinner table and worrying about the mess he inevitably made. Afterward, a few friends told me that my plan was a good compromise.

When Bob was diagnosed with Alzheimer's disease, I knew that our lives would change, but I was focused on managing his disease and preserving his quality of life. I didn't give much thought to our social lives, so it never dawned on me it would need to change—even though it made perfect sense, since so much of our lives would change as Bob's disease progressed. I guess I couldn't predict how important it would be to keep our social world alive.

I don't want to give you the wrong impression. We really weren't all that social, especially compared with some other couples we knew. Aside from holidays and special events like weddings, we'd gather with friends every few weeks for dinner or concerts. It was a nice part of our routine as a couple—and important to us both.

But between the two of us, Bob was the outgoing one. While I was the one who planned our events, as women often do, Bob was our social emissary. He loved people and was gifted with the ability to talk to anyone. So, when his cognitive skills began to decline, I wasn't ready to deny Bob the joy of socializing. I was aware of socializing as a key element of Alzheimer's care, helping to keep the mind active. But looking back, I've come to realize that staying socially connected meant something deeper to me: It gave me a sense of normalcy in our lives at a time when that was diminishing day by day as Bob's symptoms worsened.

Some of our adjustments were straightforward. When Bob started losing his ability to read a menu or when making menu choices became tough for him, he would cleverly let me order first and say, "I'll have the same." Over time, I would simply order his favorite dishes on his behalf.

Other changes were more difficult to deal with. When incontinence first set in, I could simply remind Bob to use the bathroom. But as his cognitive function declined, I would need to stand outside the bathroom waiting for him. It eventually got to the point where I would just go in with him. I remember one night out at Chez Panisse, Alice Waters' restaurant in Berkeley. As I escorted Bob to the beautifully decorated but tiny bathroom, trying to ignore the curious onlookers, I told myself I didn't care—I'd be damned if I wasn't going to give him the care and support he needed. Our friends got used to our "ritual" when we visited their homes.

Loss of mobility was also a factor for some events, forcing Bob and me to sit apart from our group of friends in a handicap-friendly area, or getting in and out of the car. When I went on an outing just with Bob, this maneuvering seemed routine, and everything felt like a normal evening. But with friends, I felt pressure if I was keeping people waiting or needed their help.

As Bob's motor skills deteriorated, dining became a bigger challenge. I developed an immunity to the looks of surprise and pity when I cut up Bob's food for him. But I couldn't ignore his messy eating. Bob never lost his ability to use silverware or chopsticks, but when he ate, food seemed to fly in every direction, landing on his clothes, the table, the floor. I became more and more anxious as the meal went on, fashioning makeshift bibs out of napkins, picking food off the floor, policing the table for messes.

Buffet dinners and receptions were a different story. I remember the hostess at a fundraiser telling me, with a touch of sadness in her voice, "I really admire you for the way you take care of Bob. I don't know how you do it," as she watched me fetching water, refilling Bob's plate of appetizers, pushing his wheelchair so he could see the beautiful displays of food, and parking him if I could at nearby tables. Yes, I was busy, but somehow these settings were more manageable, almost freeing. With so many people milling around, I didn't feel as conspicuous helping Bob as I did in regular restaurants.

Socializing at friends' homes presented different issues. Not all friends were willing to deal with Bob's symptoms. And some houses just weren't well suited. I would understand, with no hard feelings, when we were no longer included in gatherings at homes with fine decor. Moving the party outdoors was a practical option, when available. Some friends offered the generous and practical solution of bringing meals to share to us.

Eventually, I became overwhelmed by my own obsession with Bob's eating habits and keeping him and the area around him tidy. So even though invitations from good friends always included both of us, I started going to dinner parties alone.

But getting together for dinner was not the only way to socialize as a couple. Concerts, movies, museum visits, sing-alongs, and storytelling were favorites for Bob and me, although in our culture these activities almost inevitably end with a meal where people can talk about the event.

Not all couples will be willing to go the extra mile, making adjustments to stay social. But for Bob and me, it was worth it. As so much else was being taken away, I wanted to give Bob the chance to enjoy something he always loved, and do the best we could as a couple to fight this disease.

Lena Chow Kuhar

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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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