



## TRANSCRIPT

# Getting Started— Tips for the Newly Diagnosed

Hearing news about a diagnosis, for ourselves or our loved ones, can be a devastating, confusing, and difficult experience. To help our listeners find the way to some helpful information, and look for guidance on getting started, we've curated content from past episodes that our audience has found to be the most useful—in understanding the basics about dementia care, learning about lifestyle practices we can adopt to slow the disease, putting together a daily routine that works and helps both the caregiver and the person who has been diagnosed, and thinking about what a care team might look like.

### *Five Key Elements of Dementia Care*

It was the fall of 2013, a year after Bob was diagnosed; I'd just started coming to terms with his illness. We had gotten a few things into motion—a support group and connecting with the Alzheimer's Association—and we were trying to figure out what lay ahead. A routine trip to visit my daughter led us to Dr. Arnold, at that time the director of the Penn Memory Center in Philadelphia.

What Dr. Arnold said to me that afternoon would inform every single decision I made for Bob, giving me the most valuable gift: a framework for caring for him. After listening to my barrage of questions, Dr. Arnold explained to me that there were five key elements of dementia care to keep in mind as I made choices to give Bob the best quality of life for the longest time possible. I don't know if I wrote them down, but from that point on, not a day went by without my thinking about them.

As Dr. Arnold explained it, the five key elements to keep in mind are medication, diet, exercise, social interaction, and cognitive therapy.

It seems so simple, but in a world that felt like it was crumbling beneath my feet, the five elements helped keep me grounded. Over time, I learned that they overlapped ... managing one element often had a positive effect on others.

The mention of medication brought up something that I've learned in my years in health care communications,

that following a drug regimen is critical; drugs don't work unless they're taken.

To ensure that happens, there usually comes a time when caregivers need to take over. In addition to two medications for Alzheimer's, Bob was taking medications for other health problems. So it was especially important that I take ownership of his medications, make sure they were taken as instructed, and that refills were ordered in time so there were no disruptions. Fortunately, it was early enough in the course of his disease that we could discuss it. And Bob was an easygoing person, so he happily allowed me to take over—which was kind of the dynamic of our relationship anyway.

As runners, Bob and I were fairly conscious about what we ate. So we wondered whether a diagnosis of Alzheimer's disease would call for a change in our diet. Dr. Arnold recommended the Mediterranean diet—which is well known for its heart-healthy benefits, but there's also some evidence it can help stave off Alzheimer's-related changes to the brain.

Bob and I were already big fans of fish and vegetables, so it wasn't a big leap to cook with fruits, vegetables, whole grains, and lean protein—the staples of the Mediterranean diet. One of our biggest challenges was cutting down on carbohydrates—pasta, bread, potatoes. So, yes, we cheated a little here and there. Life with Alzheimer's is tough enough without the occasional guilty pleasure, which for Bob was bread and cereal, and for me, ice cream.

Dr. Arnold didn't need to preach the benefits of exercise to Bob and me. Since we were runners, it was central to our routine. But when I learned it was important to the health of a person with dementia, I realized that I would need to consciously continue to make exercise a part of Bob's routines.

In Bob's case, vascular dementia contributed to a loss of coordination and fluidity in his movements ... eventually his gait became awkward, and I could see in his eyes that

walking took some determination. But we discovered different ways to make exercise work. We introduced a walker—I remember him stepping away from his walker momentarily to shoot hoops. To maintain muscle tone, Bob lifted weights and continued doing push-ups—but modified to do while standing up.

I also found that very often, exercise means interacting with other people—walking, dancing in a group, working out in a group—rather than isolation.

The day before he passed away, Bob was doing hand weights in his wheelchair—by that time he was no longer able to walk on his own. I found it comforting to feel his strong grip, and to see the inevitable smile, when he was up and about, exercising at the level that he could.

Next on the list of five key elements was social interaction, which benefits Alzheimer’s patients by keeping the mind active. I remember other caregivers in support groups talking about needing to keep their loved ones at home full time for the best care. What they didn’t realize was that they were depriving their loved one of social interactions—to say nothing of depriving themselves of a break, which is so important but often overlooked.

Knowing the importance of social interaction, both personally and for his disease, helped me make the decision to enroll Bob in a day care program, even when he was still largely independent. Sure enough, Bob became one of the best-liked members of his day care program. At first, he would hang around the coffee pot and chat. Later, I would find him clapping enthusiastically when someone told a story. Or, later still, he might wake up from his “snooze” as he called it when people started music or games.

The fifth key element, cognitive therapy, or cognitive training, was actually one issue on my mind before we saw Dr. Arnold. I first heard about it through the Alzheimer’s Association and was considering in-home programs offered by a group in our neighborhood. We opted for in-home cognitive therapy, but as I learned, many adult day care programs include some form of cognitive therapy.

Not to be confused with cognitive behavioral therapy, a type of psychotherapy, cognitive therapy focuses on improving cognitive skills—such as thinking,

concentration, language, and memory. It’s a kind of exercise therapy for the brain.

Twice a week, in 75-minute sessions, a trained cognitive interventionist would engage Bob in conversation, encourage him to tell stories, work on puzzles, solve math problems, and play games on an iPad. Often, as a warm-up, the interventionist would go for a walk with Bob. His monthly progress was tracked by his ability to engage and focus, as well as overall cognitive skills.

As Bob’s Alzheimer’s progressed, and solving math and picture puzzles became too difficult, therapy shifted toward art and music. Even the week before he passed away, when Bob was physically too weak to go to day care, he completed a painting with the supervision of his art therapist—a piece of art that graces the entry hall of my home now.

Medication. Diet. Exercise. Social interaction. Cognitive therapy. These five key elements were central to all my decisions for Bob’s care. I used them as a checklist when I began to put together a care team, evaluate day care programs, interview home care staff, and decide between home care and long-term care facilities. Day to day, I used the five key elements as mental touchpoints as I planned out Bob’s day, his meals, and his activities. Even today, as I look up from my desk, I have vivid memories of Bob walking with Miriam, one of two favorite regular caregivers, singing “You Are My Sunshine” as he started his day.

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*One of the first steps we can take is to think about our lifestyle, and what we can do to stay healthy. Our guest speaker, Dr. Steven E. Arnold, talks about lifestyle practices he recommends for Alzheimer’s patients at the time of diagnosis—recommendations that can also benefit the health and well-being of family members by reducing the risk of developing the disease. Dr. Arnold is Professor of Neurology at Harvard Medical School, and Translational Neurology Head and Managing Director of the Interdisciplinary Brain Center at Massachusetts General Hospital.*

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*After Diagnosis: Lifestyle Practices*

As a physician specializing in memory disorders including Alzheimer’s disease for over 30 years, I have

come to appreciate how many different ways the disease expresses itself, and the many unique ways patients and families experience their journeys. But with all these differences, when families first hear the diagnosis, the spoken or unspoken question is the same: What does the future hold?

I answer that, regardless of the form or the type of neurodegenerative disease your loved one may have—Alzheimer’s disease, vascular dementia, Lewy body dementia (related to Parkinson’s), or frontotemporal dementias, to name a few—you can expect the disease to progress. Over time, these brain diseases erode a person’s life, their ability to think, remember, communicate, and care for themselves. The deterioration is often slow and subtle at first, and people can live a good-quality life for some time, even with memory loss. But it does progress, and abilities that give us independence worsen. A heart-wrenching point of progression arrives when a person no longer recognizes their spouse, children, or other loved ones. Ultimately, the brain degenerates and fails to the point that the person can no longer feed themselves, maintain bladder or bowel continence, talk or walk. When people ask what exactly kills you with Alzheimer’s disease, if it’s not another illness like a heart attack or cancer, it’s usually a complication of basic functions—a urine infection that spreads to the blood, for example, or swallowing difficulties where the food goes down the wrong pipe, leading to aspiration pneumonia.

In terms of life expectancy, rough statistics estimate 7 to 10 years from the time of initial symptoms. But I’ve given up trying to predict for any individual. I’ve diagnosed people when they were still working, and then just two years later they needed round-the-clock nursing care. On the other hand, I’ve seen people golfing and going on family vacations 15 to 20 years after diagnosis.

At diagnosis, people are eager for a prescription, something to slow or stop Alzheimer’s in its tracks. Unfortunately, current treatment offers only modest benefit, and while the research is promising, we aren’t there yet.

While I can’t offer a cure, I strongly emphasize common-sense lifestyle practices that benefit any individual—but

are particularly important for people with Alzheimer’s disease or other dementias.

Cardiovascular health is key. High blood pressure, diabetes, and high cholesterol promote vascular disease and afflict many people in the general population, but they’re also associated with Alzheimer’s and most types of dementias. So it’s important to keep in close contact with your primary care physician to manage these risk factors.

On a similar note, exercise is important. There’s been a lot of compelling research about how a sedentary lifestyle sets us up and promotes dementia later in life. Physical inactivity, weight gain and obesity in midlife, and loss of muscle mass in later life are all associated with earlier age of onset and more rapid progression of Alzheimer’s disease and other dementias. Any investment in physical and aerobic activity pays huge dividends in brain health and resilience to dementia. Do what feels right for you. If you are pretty sedentary, it could be spending more time on your feet moving about the house, gardening, or walking in the neighborhood. It could involve more focused activities like group exercise classes, dance, or running. Whatever works for you, the more you get your blood pumping, the better.

Diet can play a key role in the care of Alzheimer’s patients. The Mediterranean or DASH diet is for many of us a manageable way to eat healthy. This diet has plenty of variety, with an emphasis on lots of fresh, colorful vegetables and fruits, whole grains and beans, nuts, healthy fats/oils like extra-virgin olive oil, fish, occasional low-fat meats like chicken, limited dairy, only very occasional red meat, an occasional glass of wine, not more than one a day, and avoiding highly processed foods, refined sugars and carbohydrates, and salty foods. When you apply these guidelines, you’re covering your bases by lowering the risk not only of Alzheimer’s but many other chronic diseases. And very likely you’re slowing the progression of Alzheimer’s. I’m sometimes asked about the effects of other diets like vegan, keto, and paleo on Alzheimer’s disease and I say the data aren’t there yet to say one is better than another—none has proved any more beneficial than the Mediterranean-type diet.

Do not underestimate the importance of sleep. Recently, there's been lots of fascinating research showing that harmful amyloid proteins and other metabolic waste products of the brain are cleared during deeper stages of sleep. Getting enough deep sleep stage can be a challenge for older people in general and those with Alzheimer's disease in particular, whose sleep tends to be more fragmented. Sleep specialists, however, offer many recommendations to improve sleep hygiene.

Consider your sleep environment. Make sure your bedroom is quiet, dark, and cool enough for comfortable sleep; also, avoid the stimulation of TV, radio, music, and blue light-emitting screens right before sleep. Get your body in the habit of a natural sleep rhythm by adjusting your sleep schedule—try to go to bed around the same time every night and get up at about the same time every morning. Get your body in the mood for sleep. This means avoiding taxing situations, or in the case of caregivers, stressful tasks and work, before bedtime to let our minds calm down. It also means not overeating near bedtime, relegating caffeine to early in the day, and avoiding nightcaps since alcohol does disrupt sleep. Many people take antihistamines like diphenhydramine, found in Tylenol PM and other over-the-counter sleep medicines. While they may make you sleepy, they have side effects on other brain chemicals that worsen memory and concentration abilities and should be avoided.

Stress, mood, and anxiety: This is a complicated area. There's evidence that people who tend to experience more psychological distress in their day-to-day lives have a higher risk of developing Alzheimer's disease, and have a faster rate of progression once they do. We all have stress in our lives. Regardless of whether the amount of stress is normal or excessive, it's how we manage it that is important. Some stress is actually stimulating to the brain. Too much or mismanaged stress is destructive. Chronic stress has a wear-and-tear effect on the connections of the brain, making them more vulnerable to diseases like Alzheimer's. Time for relaxation, practicing meditation, mindfulness, yoga, tai chi, walks in the neighborhood, or just enjoyment of leisure activities should be built into the day. But when stress becomes overwhelming, or when depression and anxiety take hold, it's important to get professional

help with either counseling or medicine or both. I'm speaking here of the caregiver as well.

Cognitive stimulation is important. I'm often asked about specific brain exercises to improve memory or other cognitive abilities. I don't think the data on brain training are good enough yet to recommend any specific exercises. However, we do know that *lack* of mental stimulation may be harmful by making the brain less able to compensate for the disease changes that happen in the Alzheimer's brain. It's helpful to stay intellectually engaged with mind-stimulating activities. Consider ways to keep the mind alive and working. Depending on capability, this might involve volunteer work, promoting new experiences in travel, day trips, museum visits, or just reading. Choose engaging TV shows, do crossword puzzles and word searches, and play games that involve strategy.

Social interaction can be seen as a form of cognitive stimulation. There's nothing more stimulating to the brain than exchanging ideas and emotions with other people. We are, after all, social creatures: Our brains are hardwired for relationships and thrive on interaction. But as people age they may retire from work and lose those built-in workplace interactions. Friends and family members die. Arthritis and other physical ailments may make it harder to get out of the house and socialize. As their worlds shrink, people lose the mental stimulation of being with other people, hearing about new things and communicating their own ideas. Isolation can also lead to loneliness and depression, and these conditions are toxic to the brain.

On a related note, we're starting to recognize the role of hearing loss in cognitive decline. If you think about it, our ears are perhaps even more important than our eyes as a conduit to the world, especially the social world. With hearing loss, less information is reaching the brain, making it harder to register in memory. Older people who develop hearing impairments have more difficulty understanding and remembering, and may become more withdrawn. It's wise to get tested and get hearing aids.

Cardiovascular health, diet, cognitive stimulation, sleep, and social interaction. They're important areas of consideration for both the person suffering cognitive decline and the caregiver, to help improve quality



of life and reduce the risk of disease. These lifestyle improvements do double duty by slowing disease progression while helping to keep the healthy mind healthy for as long as possible.

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*Caring for our loved ones with dementia is a challenging task. In this episode, Lena talks about how she began to figure out the help she needed and find it, even though getting help—and letting go—can be challenging.*

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#### *The Care Team*

Moments before Bob's memorial service, looking over the crowd of family and friends, I caught sight of my daughter, Andrea, with her two children and her husband, Steve, who was watching the door. Suddenly, Steve shot from his seat to greet a new arrival. It was Thomas, one of Bob's most beloved caregivers. As we had planned, Steve ushered Thomas to the empty seat in the front row, reserved for family.

Thomas is indeed family. Over the last six months of Bob's life, Thomas barely left Bob's side. He was one of several caring and knowledgeable members of the team who ran this last marathon with Bob and me. This care team, all professionals with specific areas of training, became Bob's lifeline—and mine.

I knew little about Alzheimer's care, but I did know this: I was facing a difficult and unmarked road, and I would need someone to help me navigate it. I didn't need to go far to find Stephne, a care manager familiar with the issues confronting aging adults with dementia. She was referred by Vicki, director at an age-in-place community literally around the corner from my house. Stephne was my go-to consultant and confidante, a trusted sounding board who guided me and talked me through decisions I made for Bob, large and small. Should he start day care? Which day care centers should I check out? When should I start looking for home care help? Stephne anguished with me over whether I should keep Bob at home, or whether a long-term care facility would be better for Bob—and for me.

And when Stephne did finally recommend home care, it was possibly as much for me as it was for Bob. At that point, Bob was still what professionals would call "high-functioning." He could still manage his day-to-day activities. He could still speak, read, and write. But we

knew this would most certainly change. Before it did, Stephne knew it would help for me get used to the idea of someone else caring for Bob. So we started with home care twice a week for two or three hours.

Our first home care helper would mostly just chat with Bob and do some light housekeeping. Bob would say to me, jokingly, "So what time's my babysitter coming today?" As Bob's condition worsened, the home care visits became more regular. An aide would arrive when Bob came home from day care, and stay until I finished my work and was ready to make dinner. This schedule evolved into an early morning shift to help Bob get up, shower, and dress for the day—with the level of help increasing with Bob's needs.

Stephne shepherded me through these transitions, and helped me screen for the right people at each stage. Were they willing to engage in conversation and activities such as walking, singing, painting, or solving puzzles? Would they be respectful of my rules—for example, not allowing TV watching until after dinner? Were they genuinely interested in caring? Bob and I were fortunate to settle down, eventually, with a superb team of compassionate home caregivers who stayed with us for several years. Miriam, a blessed soul with smiling eyes whom I connected with right at our first meeting, took the morning shift. Thomas, her nephew, came in the afternoon. Later, when Bob's restricted mobility required someone to help lift him in and out of the wheelchair, Miriam had to relinquish her duties to Thomas.

Another central person on our team was Florence, the social worker and director at Rosener House, the wonderful day care center that Bob attended for five years. I so appreciated Florence's clear, direct but compassionate assessments of Bob, and the support group she led for caregivers. Kathy, at the front desk, always made me feel as though Bob and I were the most important people ever to walk into their facility. I learned the importance of cultivating trusting, positive relationships with key people at day care; their close, professional watch on Bob kept me in touch with the inevitable changes in his condition, giving me the information I needed to respond in a timely way.

When Bob first signed up at Rosener House, he was still driving occasionally. With Florence's wise guidance and gentle insistence, I found a driver to bring Bob, along

with a few other attendees, to Rosener House. Jack drove a minivan and always wore a cowboy hat. He had a cheerful, upbeat personality, always starting Bob's day with, "How are you doing, Champ?"

Knowing that exercise is integral to dementia care, and because Bob enjoyed being athletic all his life, I decided to add personal training to the group exercise he was doing at Rosener House. At first, Bob trained at the gym with Brian. After a time, he trained at home with Andre, an old friend. Andre was creative with exercise—they shot hoops at a neighborhood court and worked out at our local park. Even when Bob was in a wheelchair, Andre kept Bob's exercise regimen going with arm weights.

Cognitive therapy was a part of Bob's routine for about three years. The cognitive interventionists were typically students—young and dedicated—who brightened Bob's day with their positive attitudes, engaging conversations, walks around the neighborhood, or strumming a guitar as the session began. Later, this would be replaced by art therapy. I will always remember Monique, the art therapist, who supervised Bob's last paintings at the Alzheimer's Association office in San Jose and later at our home, only five days before he passed away.

Alzheimer's disease can take an emotional toll on caregivers, and couples. Stephne referred us to Kathy, our psychotherapist. Trained as a nurse, Kathy was a licensed psychotherapist specializing in helping families of people with dementia. She worked at a local hospital, where she ran support groups, and maintained a busy schedule with her private clients. Bob and I met with her every month until Bob was no longer able to manage the stairs to her office. I continue to meet with Kathy to this day.

The summer before Bob's passing, his physical condition started to deteriorate. It began with his heart: valve disease that required surgery. Recalling his painful recovery after open-heart surgery 30 years before—when Bob was much younger and healthier—I decided against it. Then came a blister on his foot that turned into a wound infection that wouldn't go away. During his third hospitalization for it, the surgeon discussed the option of amputation. That was when I was offered a consult with the hospice group. Thus began the last 352 yards of

our marathon, and the introduction of the final member of Bob's wonderful care team—a compassionate hospice nurse by the name of Elsa.

I was mentally prepared to make this difficult decision. From our past experiences with family, Bob and I were very clear about not wanting treatments just for the sake of extending life. Also, earlier that year, Bob's doctor had scheduled a call with me to, as he said, "talk about existential issues."

So I felt confident about discontinuing treatments that would require hospitalization and add to Bob's discomfort. And with guidance from the hospice team, including a physician and a chaplain, and knowing Bob's preference to stay home, I found home hospice to be an easy decision. This meant that, while Bob would be cared for at home, Elsa would visit regularly to check his vitals and care for his wound. Elsa painstakingly trained me to change Bob's dressing on her off days. Incidentally, Elsa's experience in caring for Bob motivated her to become certified in wound care. She completed her course work right before Bob's passing.

My experiences with our extended family of caregivers taught me so much, practically and personally. I learned to recruit people who met my criteria and to act quickly if they proved disappointing; to trust people and be committed to building a relationship of mutual respect. I learned to let other people do what I thought was only a wife's job—from personal hygiene to picking out the day's outfit. I learned to share my home and my "turf," the kitchen. In turn, the support I received nourished me emotionally, and allowed me to continue building my career and to take care of myself—while making sure that Bob's days were as healthy and full as they could be.

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*Another helpful tool to consider is developing a daily routine—a schedule that sets some time windows for getting up to start the morning routine, meals, walks, activities, or when help is expected to arrive and take over some of the tasks. This is especially helpful if there are multiple people on the caregiving team, whether formally or informally. Routines can easily be adjusted over time, with new needs and resources, but they are a good start for regaining some sense of normalcy.*

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*Daily Routine*

It is fair to say that few people know me better than my therapist, Kathy. Over the years, I've sat on the couch in her office, often with Bob, always with fresh flowers on the coffee table, and confided my fears and my hopes as a person, as a caregiver, and as a wife. Recently, as we were reminiscing about Bob, we laughed recalling how I used to pack his schedule with activities, as though to crowd out any chance for his decline. But then, in all seriousness, she said that it may have, in fact, worked. Keeping Bob active not only helped improve his quality of life, but possibly slowed some cognitive changes.

Looking back, I never planned to crowd Bob's schedule. It happened gradually, starting purely as a practical need to get organized so I could give Bob the care he needed while continuing my own work and activities. As Bob's level of function changed, his daily routine became more elaborate, and my role evolved into one of manager, working with home care and day care aides, and over time, coordinating activities through a network of services, support groups, and senior centers.

The routine changed over time, but his days were never without structure.

Bob's day started at 8 am, pretty much on the dot, and usually ended at 8 pm as he got ready for bed—though bedtime might vary to make room for a movie, concert, or gathering with friends, especially over the weekend.

Early on, I made a few rules for the home care team. One was that Bob could not lie down during the day. It was okay for him to nap sitting up in a chair—what he called a “snooze”—but the bed was for nighttime sleep only. I believe this routine helped ensure Bob would consistently get a good night's sleep, so important to his health. It wasn't until the last months before his passing that Bob's sleep got more erratic. He would wake up in the middle of the night and, quietly and inexplicably, start moving his legs.

Bob's morning routine was the same to the very end: toilet, shower, shaving, and getting dressed, which helped set his daily rhythm in motion. He was always ready for the day about 30 minutes after waking, well-groomed, in good spirits, and prepared for breakfast. I believe that even this simple goal helped Bob start his day with a sense of purpose and retain his sense of self. I still have beautiful memories of

Bob smiling at me and saying, “Good morning, Lena” as he walked by my office on his way to the kitchen for breakfast.

Every day from Monday to Friday, Bob's core activity was day care. At 9:30, Jack, the driver, would bring Bob to Rosener House for his four to five hours of group activities—discussion of current events, exercise, art, music, plus lunch, coffee breaks, ice cream socials, and an occasional outing. Knowing that social interaction is a key element in dementia care, and knowing Bob's natural affinity for people, I viewed Rosener House as the most important activity of his day. From my conversations with fellow caregivers over the years, I've learned that some loved ones refuse day care. I always felt very sad for them, for what they were missing—the power of social interaction in slowing cognitive decline, and the respite for caregivers while their loved ones are safe and secure in a supportive environment.

Bob engaged in a variety of activities after day care. Workouts with his trainer, Andre, twice a week. Cognitive therapy twice a week. Time with his caregiver Miriam or Thomas for walks, reading the newspaper, listening to music, reminiscing. Bob loved talking about his days as an engineer working on the space shuttle. He also enjoyed sharing pictures and telling stories about his parents, proud immigrants from Slovakia, and his childhood in Yonkers, New York. Bob's days were richly active. Which brings me to the second rule I made for our home care team: no TV until after dinner. In my mind, watching TV is too passive, and it could not replace the activities that engaged Bob, and helped slow the decline in his verbal and other cognitive skills.

Bob liked sitting in the kitchen watching me make dinner. Afterward, we both enjoyed *Jeopardy* and then *Wheel of Fortune*. Bob would delight me with his observations about Alex Trebek, like “He doesn't have his mustache this week,” or “He has new glasses.” On occasion, he would solve a puzzle on *Wheel of Fortune* and look quite pleased with himself. I was ecstatic.

We both also loved going to our local bookstore, Kepler's, for events. One particularly memorable experience was meeting Elizabeth Strout after the release of her book *My Name Is Lucy Barton*. Likely noticing Bob in his wheelchair, Strout beckoned us to the front of the queue, greeting us warmly and signing Bob's copy of the book.

By that time, Bob was no longer reading books on his own, but he liked being with me and the energy of the people in the room.

Our Friday date night was sacrosanct. I would leave work mid-afternoon to meet Bob upon his return from day care, and we'd go straight to the movies—popcorn and diet soda for Bob, and a hot dog for me. Afterward, we would have dinner at a favorite restaurant. Over time, I settled in on two restaurants that were most accommodating of our needs—Bob was a bit of a sloppy eater and, later, bound to a wheelchair, which made navigating the tables difficult.

Bob and I always enjoyed cultural activities, and this continued over most of the course of his disease. We shared a special love for music, and attended concerts at the local venues, or in San Francisco at Davies Symphony Hall on a Sunday afternoon. We hosted recitals at our home periodically. I was a member of a local music group called Fortnightly Music, which held public concerts and private recitals at members' homes. Bob enjoyed listening to me on the piano and in duet with my flute-playing friend Deborah. He always applauded enthusiastically, and afterward took in the buzz of the room with a quiet smile while everyone shared a glass of wine.

We visited museums and went on art tours hosted by the Alzheimer's Association. When the Panama Canal celebrated its 50th anniversary, we saw the exhibit at the De Young Museum in San Francisco. I'll always remember the very last Memorial Day with Bob. Together with Thomas, his caregiver, we spent the day at the San Francisco Museum of Modern Art for the Magritte show.

Routines are meant to be broken—I felt it was important to be flexible. Often, I would ask for Bob to be excused from his day care programs to attend events I thought he'd enjoy, like a neighborhood storytelling hour or sing-alongs hosted by Avenidas, our local retirement-in-place community.

I did my best to keep our weekend routines very much like those of other older couples. Shopping in the mall, dim sum—Bob's favorite—or dinner with friends. Church on Sunday. But we were always happy to make time for family. Bob's children—two sons, two daughters, and their families—would travel from as far as Kentucky to spend time with Bob, live up his weekends, and show their love

in their own unique ways.

His son Chris, who lives only about an hour away, would visit for the day with his partner, Werner, and their daughter, Tessa. They loved a trip to nearby Filoli Gardens, followed by dim sum. Bob's daughter Kim and her husband, Tom, would drive up in their truck from New Mexico on occasion. Bob and Kim shared a love for the outdoors, and he always enjoyed riding in the truck, getting updates about Kim's work as a forest ranger. Visits with his daughter Liz, from Kentucky, tended to have a more sentimental, nostalgic timbre. And when Mike came from Southern California, they talked about boats and we'd go for brunch at the beach.

These occasional detours from the normal routine helped break the monotony, and made returning to the regular schedule even more rewarding, and perhaps comforting. I'm still moved by Bob's deep relationship with his children, individually and as a group, and always admired how they stood by him—and each other—through difficult times.

Bob's activities might have changed as his function declined, but his days were never without structure. I believe the structure was not only important for practical reasons, but also helped fill an emotional need for stability while so much else was changing, replacing uncertainty with predictability—a much-needed constant in a constantly changing world.

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*The journey ahead is a challenging one. We'd like to close this episode with Lena's reflections. Is it worth it? As she gives testimony to her journey with Bob, the answer is a resounding yes.*

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#### *Love, Living, and Alzheimer's*

Amy Bloom's much publicized book, *In Love*, and her story about her and her husband's decision to end his life following the diagnosis of Alzheimer's disease shocked, saddened, bewildered, and disturbed me. Images from the years following my own husband Bob's diagnosis, the long, unpredictable journey—punctuated by anguish and despair at times, and unexpected calm and joy at others—flashed before my eyes, as I realized that I would not trade our times together for anything. While I would not think of those years as the best years of our lives together, we shared magnificent moments



feeling the deep love we had for each other, the pride in our children and grandchildren as they rallied and gave us their unconditional support, and our gratitude to all the people who made this journey possible—the clinical team; the home care staff; the social workers and support group leaders at day care and the Alzheimer’s Association; the music, art, speech, physical, and cognitive therapists; exercise instructors; drivers; and friends. If there is one thing I want the world to know, it is that an Alzheimer’s disease diagnosis does not need to spell an end to quality living, and that help and support are out there for those of us who choose to meet the challenge.

So how did we do it? How did we live the Alzheimer’s journey through all the heartbreaks?

It took us a little while—perhaps a few months—but our first step was recognizing and acknowledging the diagnosis. I remember saying to Bob, when we finally came to terms with it, when we signed up for a six-week support program for newly diagnosed patients: “We start our Alzheimer’s support group next week. The key word is *Alzheimer’s*. This is your diagnosis. This is what we are going to face together—the biggest challenge in our lives. It’s going to be tough, but we can do it.” Just a few days before that, I had visited our local senior community center—Avenidas, in Palo Alto, California, where we lived—and spoken to Vicky, a social worker familiar with the issues of living with dementia. And it was Vicky who recommended the support group and reserved places for us. The group gave us an opportunity to meet people like us, to share our feelings of dismay and confusion, gather information about what lay ahead, and ask the inevitable question, what do we do now? I found the experience of talking to others like us both encouraging and educational, and the extrovert in Bob enjoyed meeting people and chatting with them. We ended up attending support groups pretty much through all the years of his illness. All the support groups we attended were free of charge, run by the Alzheimer’s Association. Since the start of the COVID-19 pandemic, many support groups have been available online, making participation easy. Vicky also recommended a care manager. Sometimes called a case manager, the care manager is someone experienced in guiding families as they face the challenges of dementia, elder care, or serious illness.

Following an initial assessment of our situation—Bob’s diagnosis, my employment status, access to family members who could help, our lifestyle and finances—our care manager gave me an overview of what lay ahead in terms of caregiving needs, which would surely increase with cognitive decline. She talked about resources available in our area (such as day care), and longer-term needs such as advance health directives and estate planning. Care managers are consultants, paid by the hour, so I made sure I planned how I would use her time based on our budget as well as our needs. Over the years, our care manager was my sounding board on decisions—such as starting day care, choosing day care, and weighing the tradeoffs of moving Bob to a care facility or keeping him at home. She also interviewed potential home care staff and guided me in training them. At my request, she would visit the day care center to observe Bob—something only professionals are permitted to do—and report on his progress to me.

Key to keeping Bob healthy and feeling well physically was the clinical team. Bob had an excellent primary care physician who had known him for 20 years before the diagnosis, and Dr. Mebane was there every step of the way to direct and coordinate his overall care. I especially appreciated his readiness to respect and support Bob’s neurologist’s decisions. With my consent, we tried—successfully, I might add—to include experimental approaches to Bob’s treatment. This was possible even though Bob’s neurologist was in a different health care system, 3000 miles away. In turn, Dr. Arnold, Bob’s neurologist, gently reminded me, when the time came, that he had done everything he could for Bob, and that Bob’s primary care physician was my most important resource for Bob’s care going forward. Dr. Arnold also introduced me to what became a guidepost—the five key elements of dementia care. Medication. Diet. Exercise. Social interaction. Cognitive therapy. I lived by these five key elements as I made decisions for Bob, every day.

All of this—healthy daily routines, participating in support groups, making sure Bob received the best care possible—would have been far more difficult if I hadn’t been at my best, physically and mentally. I became a champion of self-care, knowing in my heart that the time I invested in staying well was time well spent, for me and for Bob. I made exercise, time for myself, music,

hiking, and enjoying my grandchildren the highest priority. Putting ourselves first is especially challenging for caregivers because of the incessant and often unpredictable demands of dementia, but it makes all the difference. In our roles as wife and mother, women like me are used to making sacrifices for our family, giving priority to their needs. And then there are practical barriers—such as having people to help with care while we take time off. Recently, *Bob's Last Marathon* devoted a podcast to the topic of overcoming barriers to self-care. In that podcast, Dr. Barry Jacobs, noted psychologist and family therapist, and Felicia Greenfield, Executive Director of the Penn Memory Center, offer suggestions on asking for and getting help, and, importantly, adjusting our mindset to give self-care the time and space it needs.

I am glad the option to end Bob's life never entered our heads as we grieved over the news of his diagnosis. And that I am here, today, to give testimony to the life and love that are possible for people diagnosed with Alzheimer's disease. Was that worth it—the hard work, the sadness as Bob suffered the never-ending loss, and the reality that the partnership we enjoyed as a couple had evolved into a caregiver-dependent relationship? My answer is a resounding yes. I know from the smiling face of Bob, in a photo taken during his orientation at day care, with tussled hair and a handwritten name tag. I know from the paintings, hanging in my home, created by Bob and our grandchildren as they shared moments of connectedness. In my mind's eye, I can see Bob sitting on our front porch with each of his children as they shared stories or just watched the world go by. And I know from the last few words that remained in his vocabulary to the end: “Thank you,” “I love you,” and “You take good care of me.”

*Dr. Steven E. Arnold is the author of the episode titled “After Diagnosis: Lifestyle Practices.” Lena Chow Kuhar is the author of “Five Key Elements of Dementia Care,” “The Care Team,” “Daily Routine,” and “Love, Living, and Alzheimer’s.”*