Bob's LAST MARATHON

Living the
Alzheimer's
Journey

Living Well with Alzheimer's Disease

PRACTICAL GUIDE TO DEMENTIA CAREGIVING

A PUBLICATION OF BOB'S LAST MARATHON FOUNDATION

First edition, August 2021

Bob’s Last Marathon Foundation is a California nonprofit public benefit corporation and public charity recognized by the IRS as exempt under 501(c)(3).

ISBN: 978-1-7375812-1-5

bobsmarathon.com

Table of Contents

Preface 5

Self-Care for the Caregiver 6

After Diagnosis: Lifestyle Practices 10

Choosing Kindness 16

I Repeat—Coping with Repetitive Behavior 20

Conversations 25

Cognitive Fitness 31

Still Bob 35

Day Care 39

Music Therapy 43

Honoring Loved Ones Through Art 48

Links 53

“This is so powerful,
thank you for sharing
your story.”

“I’m so sorry you had to walk that road
but what a beautiful way you did,
and what an act of transformation that you are
using this experience to help others.”

“Lena, I'm sure Bob is smiling
down on you now.”

Preface

How do we help our loved ones stay engaged and healthy? What about caring for ourselves? How do we communicate with our loved ones effectively? What roles can art, music, and cognitive training play in our loved ones' well-being? In this second volume of our e-book series, we share valuable experience and insights from caregivers and professionals. We celebrate the essence that remains in our loved ones and how the unexpected sparks light up our life. Above all, as the opening chapter suggests, we call on you to take on the very important task of self-care, because your well-being is essential to your loved one's well-being.

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.

Self-Care for the Caregiver

🔊 Podcast Link

Lena Chow Kuhar

Bob and I were at the orientation meeting of a support group for newly diagnosed patients and their families. I could relate to my fellow caregivers in the room. We were bewildered, already weary from dealing with the diagnosis, and struggling to keep up with the relentless changes. At that moment, it dawned on me: This is just the beginning. We were all embarking on a very long journey—years, possibly decades. Was I prepared?

Bob and I had both been long-distance runners in our younger, healthier days. I couldn't help thinking how much the Alzheimer's journey was like a marathon. This was no sprint: We'd have to go the distance. And while I had my workout routines down for marathons, I had no idea how to train for this one.

As I took in the anxious expressions of the caregivers around me, I wondered: Who or what was going to save Bob and me? I thought of how emergency oxygen masks drop from an airplane ceiling and how they say to put the mask on yourself before trying to help those around you. I knew then and there that I had to put my oxygen mask on first. Bob needed the best care I could give him, and so I had to do the utmost to care for myself. Bob's well-being was at stake. If I didn't care for me, who would care for Bob? And how could a burnt-out me give him the care he needed?

This idea makes logical sense, but it can seem counterintuitive. Our impulse as caregivers is to give all we have to those we love. Some people feel guilty about not putting every bit of energy into caring for their loved one. But it was clear to me that putting energy into myself *was*, in the end, putting more energy into Bob.

I saw the benefits of caring for myself very quickly. It kept me strong physically and mentally, and more able to care for Bob. It gave me the strength to do the physical work around the house—simple chores like picking up heavy packages, making the bed, doing the laundry, things that Bob was less and less able to do. It gave me the mental clarity to make good decisions. And because I continued activities I always enjoyed, I didn’t carry bitterness or resentment: I could be a positive companion. It is not an exaggeration to say that I’ve emerged from my experiences as a caregiver stronger and healthier, physically and mentally, than ever.

So how did my self-care workout translate into my everyday life? It boiled down to making time to stay healthy. In my case, the backbone of my self-care was an unfailing attention to healthy routines. I took care of my body by eating well, getting rest, and exercising. I kept up with a consistent exercise schedule, eight hours a week, rain or shine.

I also maintained my mental health with psychotherapy, and by carving out some time for the pleasures of life—travel, music, and friends. Bob and I continued to go to concerts. We went to sing-alongs at our local senior center. I hosted recitals at our home.

I continued my travel adventures—sometimes with Bob, sometimes on my own. Traveling has always been an important break from my busy life. When caring for Bob, I needed that respite more than ever. It helped restore me so I could return to my routines strengthened and refreshed.

Bob and I also traveled together. We went to see family and to visit with his doctor, in Philadelphia at Penn Memory Center and later in Boston at Mass General. Seven months before Bob's passing, we celebrated our 31st wedding anniversary on Kauai, our favorite island. I was worried about Bob's failing health, but his primary care doctor ran every test he could think of, and told me he found no reason for us not to go. Both his doctor and I were aware this would be Bob's last trip to Kauai. Miriam, Bob's home care person, came with us. I still remember that, as we got into the rental car, Bob said, "We made it."

Bob and I also had routine outings while at home. Every Friday afternoon we had a date for a movie and dinner. Over time, I would need a caregiver to help with Bob's wheelchair and transport. But we kept our weekly date to the very end.

Supporting the Alzheimer's Association also strengthened and nourished me by giving me a feeling of connectedness to others like me. I clearly remember the first time Bob and I did the Walk to End Alzheimer's Disease, on the waterfront in San Francisco. I held back tears watching the people around us. A hush seemed to come over the crowd as we began to walk. There were people of all ages, some in wheelchairs, all of us touched in small and large ways by this disease, but connected, knowing that we were not alone. The Walk became an annual event for us, but it wasn't until the year after Bob passed away that I realized how rich that experience was, walking with him—side by side, pushing his wheelchair, then having someone else push his wheelchair so we could walk holding hands.

To me, giving our very best to our loved ones doesn't have to mean sacrificing comfort and pleasure. Years into Bob's care, there were times I felt discouraged as his disease progressed. But because I cared for myself, I was not burned out. I stayed healthy and was happy to the extent that I could be, and therefore I was a better companion for Bob. I did not sacrifice my personal joys to his care, so there was nothing to feel bitter about. And when the end did come, I was able to find the strength within myself to grieve, while honoring him by pressing on with my life.

Lena Chow Kuhar

After Diagnosis: Lifestyle Practices

🔊 Podcast Link

Steven E. Arnold, MD

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.

Steven E. Arnold, MD
Professor of Neurology
Harvard Medical School
Managing Director
Interdisciplinary Brain Center,
Massachusetts General Hospital
www.actru.org

Choosing Kindness

🔊 **Podcast Link**

Alexandra Morris

Hi, I'm Alex Morris, and over decades of experience as an Alzheimer's care coach, I've seen that caregivers can have a difficult time keeping up with their loved one's changes. It requires a change in the way we approach our loved ones, as well as a new set of skills rooted in kindness and compassion that I'd like to share with you today.

Not long ago, I spoke with a client named Mary, whose sister had moderate-stage Alzheimer's and had just moved to an assisted living facility. At each visit, Carol would ask about her house and her things. She was a long-time collector, and her house was packed with beloved objects. Mary told her the truth: The house was being sold to pay for her care, and her possessions were being given away or sold. Carol reacted with great anxiety, and the visits and calls would end badly—with Carol's distress and confusion sometimes lasting for days.

While at one time the sisters were able to have honest conversations, the person Mary had known most of her life was now different. It wasn't Carol's fault; it was her illness. Carol had changed, but Mary's way of communicating with her had not. Clearly, it didn't work for Mary to treat Carol the same way she always had.

If telling Carol the truth caused so much pain, then what *could* be done to ease it?

My answer is: First and foremost, be kind. If we can be truthful without being unkind, great. But if we can't tell the truth without causing pain, we should choose kindness.

Being kind to Carol meant telling her what she needed to hear, that the house was fine and her things were untouched. In short, to lie. But Mary would not lie. The sisters had made a pact long ago never to lie to each other, and she felt she should never break it. However, things had changed. Today's harsh reality was that telling her sister the truth caused Carol great distress. Mary was hanging on to an outdated idea of Carol. In the end, Mary was serving herself, not helping Carol. It took Mary a while, but changing her approach helped relieve her sister's distress and improve their relationship.

Let me say again: If you can't be both truthful and kind, *please choose kindness*. Don't use the word "lie" in your head, but instead think, "What answer can I give right now that will help this person? What is the kind thing to do?"

There may be a reason that prioritizing kindness over facts can be so effective. With dementia, the cognitive function may decline, but emotional memory often remains very much intact. Even when people with dementia can't remember the content of a conversation, or the conversation at all, they will remember how you made them *feel*.

Susan had moderate dementia, and her sister told her that a beloved brother was very ill and might die soon. When I arrived for my visit, Susan was crying and wailing over and over, "The man is sick. The man is dying." I didn't know who "the man" was, but clearly the narrative had to change quickly.

I took her hands and looked into her eyes and said calmly, "Good news, the man is better." She said, "How do you know?" and I replied, "I spoke with your family. So please don't worry as everything is better now." Then I added, "You are all right. Let's celebrate with some Baskin-Robbins ice cream."

Susan's situation is a good example of a few skills I put into practice.

First, as mentioned earlier, when you can't be truthful, be kind. Susan could not process her brother's illness, and it caused her enormous distress. I chose to be kind and say he was better.

Second, folks with dementia tend to respond to emotional content. She was anguished because of her strong emotional connection with her brother—which is also why being kind, an emotional strategy, was effective.

Third, be reassuring, and move quickly on to something pleasant. I told Susan, "You're all right." I ended with an offer of ice cream because I knew she loved Baskin-Robbins. You can change the tone of the conversation from distress to celebration.

Finally, remember to keep your words short. Literally count them. More than ten words at a time usually is counterproductive. "Good news, the man is better." Six words. "You're all right." Three words.

Words of explanation should be short—but words of love, praise, reassurance, joking, and kindness can overflow.

It's not always easy to reroute a conversation. Your strategy should always come back to: What will he or she respond to, what will make emotional sense to my loved one? Here's a common example.

It's no longer safe for your dad to drive. But he thinks he's just fine. You have to break the news that he can't. Because driving is important to people, this conflict is likely to come up repeatedly.

One option is to try to deliver the truth in a kind way: "Dad, I am so sorry but you can't drive anymore. The DMV took away your license." It may work. If it results in anger, even an argument, you know that next time you should have a few different approaches ready. In this situation, I asked the caregiver, "What does your dad value? Is he the type to help others? Is there a family member who needs a car right now?" The answers were all "yes"—a beloved grandson had just graduated from college and was in need of a car.

So the next time driving came up, the caregiver could emphasize emotional gratification, with something like, "Oh, I'm so happy you could give Steve your car. He's thrilled! It was so kind and generous of you, Dad. You're the best." Words of love, praise, reassurance, and kindness overflowing.

Hard to believe, but it worked—and it worked every time Dad asked for the car.

I want to acknowledge that it's not always easy. But often it's not as hard as we feared *if* we are willing to be creative and try different approaches—always aiming for the kind response.

As with anything you want to be more proficient at, you must practice. Practice with other family members, friends, in front of a mirror. Then you should be ready for the words to come out smoothly and with sincerity.

Your words may not always be factually true, but the intentions and sentiments will be sincere. When you speak from the heart, when you choose kindness and connect to an emotional truth, it's your sincere attempt to help your loved one and you live your best possible lives.

Alexandra Morris

Geriatric Care Manager
www.youtube.com/watch?v=rkn8hxaoqIw

I Repeat—Coping with Repetitive Behavior

🔊 **Podcast Link**

Alexandra Morris

Loss of short-term memory is often one of the first changes that affect people with Alzheimer's and other dementias—and the resulting repetitive behavior can be among the most difficult to handle. I tend to break repetitive behavior into four categories:

- Questions regarding the schedule: "What are we doing today?"
- Questions related to whether something was done: "Did we feed the dog?"
- Questions about future events: "When is Anna visiting?"
- The fourth category is not always a question, but a common behavior—repeating the same story: "Did I tell you about the time Laura hurt me?"

Coping with repetitive behavior in any of these categories can be frustrating, but keep in mind that your loved one truly does not remember. So reminding them that you just told them won't help—and may lead to anger, confusion, or depression.

How, then, can we deal with this annoying pattern in a way that promotes the best quality of life for our loved ones, and for us?

Here are some strategies that have helped families I work with.

A strategy I recommend that applies to most types of repetitive behavior is to keep your answers short. "Our doctor's appointment is at 2 pm." A few words are much easier to say, and for your loved one to remember, than a long explanation. And the longer the explanation, the more chance it may trigger other anxieties.

On a purely practical level, purchasing a whiteboard and placing it where your loved one can see it may pre-empt the questions. Use it to list times for activities, daily tasks such as feeding the dog, and special visits. For example: 10 am breakfast, 12 pm Susan visit, 3 pm afternoon walk, 6 pm feed the dog. Knowing what's happening and when is very comforting. When I used this tactic in an adult day care program, even folks with moderate dementia were able to learn fairly quickly to refer to the whiteboard when they wanted to know what was happening next.

How you introduce the board can make a difference. Try not to say, "Mom, I bought this for you because of your memory." Too much information! And certain to create defensiveness. A good way to introduce the board is to say gently, "I got the board for us to keep track of what's going on." If she says, "I don't need that," tell her, "Well, it's helpful for me." Then change the subject.

Another approach is to remove things that might trigger repetitive questions. Before her dementia, one mom and son's pattern was to start preparing dinner at 5 and sit down to eat by 6. During that hour they would feed the dog. But the mom couldn't remember if the dog had been fed, and asked over and over, every two minutes, "Did we feed the dog?" This was driving her son crazy, so in addition to the whiteboard, I asked him to make a few small changes in the environment—and it helped: remove or cover the clock, remove the empty dog dish, put the dog out of sight for an hour or so. Out of sight, out of mind. For some folks this can make things worse as they are now constantly asking for the dog. After these changes the son reported that his mom only asked about the dog twice, and didn't ask about the food at all. When she did ask, he told her the dog was outside doing his business. She didn't feel the need to investigate. Asking twice in the span of an hour was an acceptable win.

The third repetitive behavior scenario stems from anxiety over future events. If your dad frets over future events, even pleasant ones, I recommend not telling him until the last possible moment. Reducing his anxiety is a kindness well worth a white lie. As I often say, if you can't be truthful, choose kindness. For example, "Anna just called and said she's coming over to visit. Yay, let's get ready." If that backfires, you can ask forgiveness: "Did I forget to tell you? I'm sorry." Telling Dad that you've been talking about Anna's visit all day may be truthful, but it is not kind or productive. Kindness, sometimes at the expense of truth, can be a comforting way of connecting with positive emotions, and a detour out of anxiety.

Repeating the same story is a common behavior that arises because your loved one simply cannot remember. If your husband repeatedly asks, "Did I tell you I met the new neighbor?" you can gently reply, "Yes, and she sounds like fun. I can't wait to meet her." This is a kind approach that ends on a high note. If he doesn't react well to that, then the next time say, "I'm not sure. Tell me." This approach will reduce confrontations and hurt feelings. When you have heard the story enough times, gently change the subject, start an activity, or excuse yourself from the room for a few minutes.

Sometimes, it is important to get some time away, and schedule for someone else to be the listener, rather than cut off communication and connection—which are important. Reminiscing and storytelling is not only gratifying, but a developmental need that's common to many older people, even those without dementia. And diverting to stories about the past can be a comforting way of relieving anxiety.

But problems may arise when these repeated stories cause anxiety or depression. For example, suppose your mother often turns to stories about her sister, Laura, which make her angry, anxious, and out of control. How do you break the pattern? The moment she starts with something like, "Did I tell you what my sister did?" you quickly interrupt with something pleasant by saying, "Oh, before I forget," then launch into positive topics, and have two or three things in mind ahead of time.

You can talk about family vacations ("Remember the hot air balloon festival? We had so much fun. Let's look at the photos…"), beloved family members or friends ("Aunt Stephanie called, and wow is she interesting. Did you know…?"), or pleasant events ("I loved watching the dogs at the dog park yesterday. So many different breeds…"). You can offer praise ("I sure admire your knitting. Everyone just loved getting those beautiful scarves from you last year…"). Follow up with a pleasant activity, like a favorite nature show, recorded concert, reading together, or putting up seasonal decorations. Some people want to feel useful and want to do chores. As they can, encourage and enable them to do so. Come up with a list of things they can do, with little or no help.

If Mom still goes back to her evil sister, try getting her moving. Movement and a change of scenery are powerful and effective diversions. Getting outside and exercising, when possible, are often feel-good strategies that help everyone.

Also think about the triggers in your environment—some might not be obvious. Maybe your mother's easy chair faces family photos. Even if they don't include her offending sister, they could still be a trigger. In a similar situation, I asked the family to take the photos down. Their mother didn't notice, and the subject of the sister rarely came up after that.

I've suggested ways to deal with repetitive behavior—but the forms they take are as unique as the individuals we care for. Few people know your loved one better than you. Trust your instincts, and those of others who care for your loved one, in finding ways to redirect repetitive behaviors, and reduce the stress of living with Alzheimer's disease.

Alexandra Morris

Geriatric Care Manager
www.youtube.com/watch?v=rkn8hxaoqIw

Conversations

🔊 **Podcast Link**

Alexandra Morris

As we age, almost all of us will experience some level of change in our physical health or our mental ability to process information—or both. Adapting means making changes that could involve accepting help from others to manage our day-to-day activities safely and successfully.

Even within the normal spectrum of mental or physical change, adapting may not be easy. But when dementia enters the picture, it can be especially challenging—especially because the person with dementia is often the last to realize they have a problem. In many cases, it's the spouse, adult children, or friends who first notice changes that cause concern. They are tasked with raising difficult issues with their loved one without causing negative, hurt feelings that put up walls of resistance.

How do you tell someone they should retire from driving? How do you broach the subject of needing a medical evaluation for a cognitive or physical decline they don't acknowledge? What would a conversation look like about getting help with medication management, finances, or home care? How do you speak to your loved one about their wandering or getting lost, or the need to attend social programs or day care?

Few people know how to approach these issues and, as with most unwelcome and stressful undertakings, we tend to put these conversations off for too long. The situation almost always deteriorates over time, and in worst-case scenarios, can result in their loved one being taken advantage of financially or otherwise, or suffering an injury or illness. The key is to get in front of the problem with a well-planned conversation—before it becomes too difficult, or even dangerous.

I'd like to share some tips for family and friends on how to initiate and navigate these conversations.

It's always better to plan ahead and start the conversation in the early stage, before the changes present a problem.

You can begin with gentle inquiries like, "If I saw any cognitive or physical changes in you that concerned me, would you want me to tell you?" Or an open-ended question like, "How would you like your life to be in five years?" These should be easygoing, pleasant conversations where you are listening and asking clarifying questions, rather than pushing your agenda to find the answers or form a specific plan. My main goal is to understand a person's point of view and feelings, to hear them out. To establish trust. I am setting the stage for the time when decisions will need to be made and options put into place.

So, it's important to prepare for the conversation and set reasonable expectations for yourself. Plan on the first few or maybe several conversations being just you asking questions, listening, and validating their ideas and experiences when you can.

As dementia becomes more advanced, the conversations may need to become more pointed. But again, timing is everything. Find a time when things are calm. For example, don't talk about driving just after Dad got lost in his familiar neighborhood. I once set up a time to discuss going to the doctor with a client. When I arrived, she was upset, reporting her cat got out in the morning and couldn't be found. So, I dropped my plan and proceeded to help her look for her cat, which we found, thank goodness. I rescheduled; the next time she was happy with me and open to talking. We had a very fruitful conversation.

When planning your conversation, avoid ambushing your loved one with an intervention. A surprise meeting in a room with several family members, all there to talk about one person's problem, is seldom successful and will often make things worse. Tell well-meaning family members that only one or two people should have the initial conversation. Afterwards, if your mom really wants to consult with others, help arrange it, but be sure to prepare them. Make sure they know the extent of the problems so they can be an informed advocate and a source of support.

Look for opportunities, such as when they bring up how difficult it is to cook or clean the house. Or admit to feeling lonely, or having nothing to contribute anymore. This is an invitation to a thoughtful conversation. Try not to say, "Well, Dad, I have been talking to you about getting someone in to help you out for a long time now." A better response is, "Let's talk about that. Tell me more."

Try not to argue. If your spouse says everything is fine and they don't need help with medications, try not to get drawn into arguments that will lead to denial, anger, and fear. Instead of pushing your agenda and making things more contentious, it's best to take note of the problem for a later discussion.

When presenting remedies, ask for their ideas. Their contribution not only creates buy-in, but might even result in better ideas than yours.

Also, give the ideas time to sink in. All of us benefit from time to consider options when faced with a problem. Give your loved one that time and revisit later. For example, Dad's bills are not being paid or are double-paid. You ask him if you can take over the finances and review them with him monthly. After some thought he responds that he wants to set up automatic payments with your help. For now, this meets the concern and establishes trust, and you have made some headway.

Sometimes, new remedies are best presented as being time-limited. For example, "We are just going to try the social program for two weeks and then re-evaluate."

What if you don't feel that you have the patience or communication skills to have these conversations? You can always choose someone in your care circle who does. Delegate to someone your loved one trusts and listens to. This could be a longtime friend, sibling, or religious leader. It could be a grown child or an adult grandchild, even caring neighbors.

On the same note, you can engage others to help get through thorny issues. Consider allies who maybe haven't helped yet but might be willing. I remember consulting with one family who insisted that Dad listened to no one. True to form, he wasn't receptive to any of my suggestions for starting a day program. So I put off the conversation, giving it time. In my follow-up call a week later I discovered that Dad was enrolled in the program. Aunt Susan had come to visit and had taken him. Until that moment I had never heard of Susan.

It turned out that, decades ago when their mother had passed away, Susan had stayed for weeks to help care for the children. They were very close, but the family hadn't considered getting her help, as she was having her own health problems and lived on the opposite coast. But this lucky timing was enough to get Dad started in the day program.

For times when the loved one is angry about the situation they don't understand or agree with, consider making others the focus of their wrath, not the primary caregiver. It's always better to protect the primary person when possible. For example, if Mom is angry about not being allowed to drive anymore, divert the blame in a gentle way: "So sorry the DMV took away your license, Mom. This is a very hard time." This way you are perceived as an ally and advocate, which of course you are.

Similarly, in conversations about your loved one's concerning behavior, shift the focus off them and their deficits. For example, try not to say, "Mom, we need to do something about your walking by yourself, as you have gotten lost several times and even had to be brought home by the police recently." This might result in denial—she might not remember wandering off. Or defensive anger—she is an adult and can walk whenever and wherever she wishes. In this case, being so direct, hitting the nail on the head, is more effective at building walls; she may refuse to talk with you about wandering, or anything else for that matter.

Instead try, "Mom, I think it is great that you get outside and walk around the neighborhood. I should do more of that myself. Hey, it would really motivate me to exercise if I did it with you. Can I come by tomorrow at 12 noon and walk with you? Then maybe we can grab lunch or a frozen yogurt. That would be so great for me!" Another option is to have a neighbor, volunteer, or paid person walk with her. You could tell her it's a friend who's new to the area and would like someone to show her around.

In some cases, a conversation might not be the best route.

Looking closely at this issue, what is most important? Rather than trying to reason with her, or getting her agreement, which leads to arguments, isn't the real point that she be safe? A practical solution might be a GPS tracker on her wrist or in her jacket, given to her as a gift by a beloved grandchild.

I hope these ideas will help you to start conversations and be successful in meeting everyone's needs.

Alexandra Morris

Geriatric Care Manager
www.youtube.com/watch?v=rkn8hxaoqIw

Cognitive Fitness

🔊 **Podcast Link**

Dawn Mechanic-Hamilton, PhD, ABPP/CN

As clinicians, we are often asked by patients and families what they can do to help support cognitive health and improve day-to-day functioning. There are, in fact, some proven strategies. People can make lifestyle changes such as being physically and socially active, eating a Mediterranean diet, and managing sleep difficulties. They can pay attention to their cardiovascular health by controlling risk factors such as high blood pressure, high cholesterol, and diabetes. They can also learn techniques that focus directly on *cognitive fitness*.

At the Penn Memory Center, we are working to build cognitive fitness through two groups. One is a *cognitive fitness psychotherapy group*, which focuses on building skills to reduce stress, cope with challenges and take care of oneself, and manage depression and anxiety. The other addresses the need for *compensatory strategies*, including practices to compensate for certain memory and thinking deficits.

Today, I'll talk about compensatory strategies, and use the Cognitive Fitness Skills program at the Penn Memory Center to illustrate how people can incorporate memory techniques into their daily routine to help minimize symptoms of cognitive decline and improve independence.

In our program, we begin by meeting with the patient and their care partner to get to know them. We identify their cognitive strengths and weaknesses. We learn how participants' daily function is affected by changes in cognition, how they manage these changes, as well as what has worked, and what hasn't.

Together, we create a set of personalized goals by answering the question: What specific changes would make a meaningful difference in the quality of your everyday life? By this we mean changes that translate into more independence for the participant, less burden on the care partner, and overall, greater life satisfaction for both. Even small changes can make significant differences. For example, maintaining regular contact with a friend or family member for social interaction and creating a regular bedtime routine to improve sleep can have positive effects on memory skills. We have seen that when someone takes on a chore it may ease the burden on a spouse and can improve daily life. These specific goals become the basis for an individualized roadmap and we work to put more tools in the patients' toolbox to achieve the goals and improve day-to-day function.

There are typically about eight participants in each compensatory strategy training group, who meet weekly for eight weeks. We chose the group format because people with cognitive change often share similar daily challenges, frustrations, and anxieties. A group setting allows them to get support and feedback from their peers, learn from their successes and challenges, and offer solutions based on their experiences. The focus of the program is to help participants cultivate new everyday habits that will help them function as well as possible, as independently as possible. Toward this goal, we teach individuals how to use tools such as external memory aids, internal memory aids, and home organization skills.

External memory aids are simply basic tools, like calendars or lists, that everyone has used at some point in their lives for work or specific projects. They may no longer meet the participant's needs after retirement, or perhaps were abandoned simply because of life changes. But these familiar tools may become useful again as a memory aid.

After we ask participants to identify the external memory aid they feel most comfortable using—some like paper-and-pencil calendars, others prefer a smartphone or tablet—our goal is to get everyone in the habit of using them. They are taught to use the memory aids for three specific purposes: a daily schedule, a to-do list, and journaling.

The daily schedule not only gives structure to the day, but reminds participants of upcoming events, and encourages regular activities that we know to be beneficial for people with cognitive change, like physical activity, or calling a friend. The daily schedule is tailored to the participant's unique cognitive and wellness goals.

The to-do list can function as a typical reminder of things that need to be accomplished. But it can also serve as a place to list options for daily activities, depending on the individual's self-initiation and motivation.

We encourage journaling not only as a way to reflect on experiences, but also as a tool for keeping track of important details that might prove useful later. For example, when talking to a friend on the phone, participants are asked to take notes to record things like the friend's move to a new town, a child's new job, or a grandchild's sports accomplishments. The next time they plan to speak with the friend, participants can refer to the journal as a reminder and to follow up on these events. In this way, they can also enrich their social connections.

However, there are times when external memory aids are not available or simply not practical. In these cases, *internal* memory aids, or mnemonic devices like acronyms or acrostics, can be useful. A common example is ROYGBIV, an acronym many of us learned early on to remember the order of colors in the rainbow. We know that people with memory loss have clearer memories from earlier in life. When creating mnemonics, it's helpful to pair old information with new information; for example, using a childhood home address to create memorable new passwords.

The support of someone at home—a spouse, adult child, or good friend—can really help reinforce new habits. That's why we keep care partners involved and informed through weekly updates and encourage their engagement in home practice activities. In fact, as we reach the end of the program, we make sure participants work with their home care partners to create systems that support memory and organization, and simplify daily routines—for example, making a specific spot a "home" for frequently used and misplaced items, like phones, keys, and glasses. To help someone get in the habit of using it, we might need to go overboard at first, by making a brightly colored sign to point to the "home" and catch the person's attention. Once the routine is established, the sign can be taken down.

With each new group, I stress that the work they do is a partnership, not just with the clinicians who facilitate their program, but among their fellow participants. We discuss how their collective wisdom and the creative solutions they share with one another every day are valuable, and tell them that we will pass them on to help those who follow.

Dawn Mechanic-Hamilton, PhD, ABPP/CN

Director of Cognitive Fitness Programs and
Neuropsychological Services, Penn Memory Center
Assistant Professor, Department of Neurology
Hospital of the University of Pennsylvania

Still Bob

Podcast Link

Lena Chow Kuhar

When the movie about Alzheimer's *Still Alice* debuted in Palo Alto, Bob and I had reached a sweet spot in the course of his disease: We were somewhat acclimated to the diagnosis, settled into our new routine, and enjoying a period of relative peace and equilibrium. I had read and enjoyed the book version of *Still Alice*, and was a big fan of Julianne Moore. So I asked Bob if he'd mind seeing a movie about Alzheimer's disease. In his typical magnanimous way, Bob readily agreed. After the movie, we were quiet leaving the theater, until Bob broke the silence, turned to me, and said, "Still Bob."

These two simple words filled me with mixed emotions.

I couldn't help feeling happy and grateful that Bob got it. With his wry sense of humor still very much intact, he had brilliantly captured the movie's relevance to us. And, true to his sensitive and compassionate nature, Bob was trying to reassure me—perhaps he sensed that the movie had saddened me. It was a snapshot of our future, a stark reminder of the unrelenting decline that we were facing: how Alzheimer's would quietly but mercilessly strip away Bob's basic functions, such as finding the words to participate in conversations, or enjoying a meal without making a mess at the table, or just making his way around our neighborhood of more than 20 years.

And yet, as it turned out, through all the loss that indeed *did* occur, the essence of what made Bob Bob survived to the very end. His sense of humor. His sensitivity to the emotions of people around him—smiling when he knew I was happy, grimacing when he felt I was upset.

If only I'd had the presence of mind to savor these "Still Bob" moments while they were happening.

Every time I drive the route to his old day care center, I recall how Bob surprised me one day with, "Make a left here." And, as always, "Thank you for driving"—such typical Bob kindness in acknowledging my new role behind the wheel.

Bob's early memories seemed to dominate his consciousness. For example, he spent the first years of his career right out of college in the Air Force and, later, as an aerospace engineer on the Space Shuttle *Endeavor*. Bob would often reminisce about the shuttle's launch, his team, and the astronaut, Fred Haise, who was his jogging buddy.

One summer, three years after his diagnosis, I organized a trip to Virginia with Bob and our grandchildren to see the *Endeavor*, which was on display at the National Air and Space Museum. At that point, Bob was still walking on his own, but spoke only infrequently. After admiring the *Endeavor*, we saw an exhibit of World War II airplanes. I was struggling to answer my grandchildren's questions about the planes when Bob leaned over and informed us, "These are German," and proceeded to rattle off their model numbers! There it was: a glimmer of the Bob we knew. Always the airplane enthusiast and ever the ardent aerospace engineer at heart.

Bob's parents were immigrants from Slovakia, both from modest beginnings, who made a home in Yonkers, New York. His mother, a powerful, loving influence on Bob's life, was a house cleaner. His father was a factory worker. With both parents working, Bob spent many hours with a neighboring Italian family. Photo albums from those days would jog

Bob's memories and keep him talking with our home care team, with occasional sudden lapses into Slovak and Italian. As Bob's disease advanced, he largely forgot spellings and complex words, but he never forgot his mother's full name: Elizabeth Hovanek.

Songs from the 1950s would also often surface mysteriously from Bob's past. As a newcomer to the U.S. I'd never heard the lyrics "I love you a bushel and a peck," and I still hadn't until Bob, at an advanced stage of illness, introduced them to me out of the blue. The sweet song became a comforting favorite. During his last stay at the hospital, I would ask Bob to sing it for the hospice team—and he happily obliged.

As Bob's disease advanced and he became less verbal, it was hard to know what he took in. I remember in 2016, Bob was at his doctor's office for what turned out to be his last visit at Mass General. Dr. Arnold was trying to engage Bob in conversation about current events, and the presidential election came up. By then, Bob spoke very sparingly. So Dr. Arnold asked him, "Do you know who Donald Trump is?" Bob seemed to wake up with a jolt as he declared, "He's an asshole!"

Somewhere inside, Bob's core self was very much alive.

In her book, *On Vanishing: Morality, Dementia, and What It Means to Disappear,* Lynn Casteel Harper makes a strong case for the tenacity of an individual's essence, even in advanced stages of dementia—and how this essence often goes unnoticed and unacknowledged by the people around them. I could relate. For the most part, I was just trying to keep up with the ever-shifting challenges of caring for Bob, while quietly despairing over how much he was losing—rather than savoring how much he retained, how strongly his sense of self and powerful emotions persisted through his dementia.

It wasn't until I read Harper's book, more than a year after Bob's passing, that I realized how much I might have missed.

Every Sunday morning, Bob and I attended church services and received holy communion. During the last few weeks of his life, when Bob seemed so lost in his dementia, I began to wonder if the breaking of bread meant anything to him. So usually I would go by myself to receive the bread and wine, leaving Bob with his home care person, Thomas. When Thomas could get past the crowd, he would push Bob's wheelchair to the communion table. Several times, Jonathan, who often helps as a server, would come to the pew, just to make sure Bob received the bread and wine. I was grateful but often asked myself, "Does Bob even know what's happening?" Part of me assumed he was just going through the motions. But, after I read Harper's book, I realized that Bob had not disappeared. And to Jonathan, a compassionate fellow churchgoer, Bob was very much like everyone else, waiting his turn for communion. Jonathan acknowledged Bob's presence without assuming he was a lesser person because of his diminished function. He was still Bob.

I know what I need to do when we can return to church service in person. I will go directly to Jonathan and thank him for his generosity and compassion in nurturing Bob's essence. And the next time I see families struggling with their loved ones—getting them to sit still at social gatherings, encouraging them to enjoy an ice cream despite the mess they create, going on a favorite drive after fussing about getting into the car and securing the seat belt—I want to tell them, it's so worth it. It's so worth giving their loved ones the chance to enjoy what they treasured as their undiminished self, and nurture what makes them who they are—who they still are.

Lena Chow Kuhar

Day Care

🔊 Podcast Link

Lena Chow Kuhar

About a year after his diagnosis, Bob and I started casually talking about day care. The idea was planted in my mind by our care manager, Stephne, who had started preparing us for the time at some point in the future when Bob might benefit from spending part of the day socializing with other people and engaging in structured activities. The idea hovered vaguely in the back of our minds for a few months. We even had brochures from two nearby day care centers. But we were put off by the photos of attendees, stereotypical dementia patients with untidy gray hair and a distant gaze. They didn't seem to be enjoying themselves. Bob and I agreed—"Maybe not now."

But one morning, "now" arrived.

For a good part of that year, Bob and I had a nice routine, mostly keeping to our own separate schedules. I would be out the door at 5:30 am for a workout, and Bob would get his breakfast, read the paper, and maybe take a run.

But on this Wednesday morning, Bob didn't greet me with his usual "How was your workout?" Instead he just sat on the couch, looking lost.

Over the next few days my feelings cycled from surprised, to worried, to nearly upset with him. I realized that this was a turning point. This couldn't go on. My emotions got away from me as I said, "Look at you. You look lost. I can't sit around all day to keep you company, keep you entertained." Bob responded quietly, in his good-natured way, "Okay. I'll go to the day care center," and named one of the two we'd talked about.

That was Bob through and through. Always conciliatory, agreeable, and tuned in to my feelings. He knew I was upset, and seemed to recognize he was getting on my nerves. He suggested the solution before I could.

Both facilities came highly recommended, and both were within five miles of our home. I scheduled visits and, in each case, we were received by the director, who gave us a tour, introduced us to the staff, and showed us typical daily schedules, lunch menus, activities, etc. Both made it clear that our meeting was a two-way interview. In other words, that it was our mutual goal to find a good fit, knowing that a day care decision could be a long-term one: It was a place where our loved ones would spend progressively more days, possibly for a number of years. All parties had to feel comfortable.

Even though the two centers looked perfectly fine, in the end, there were several deciding factors. While both were located in quiet residential neighborhoods, the one we chose had beautiful, expansive grounds that suited Bob's love for the outdoors. I also liked that the director, Florence, was a social worker by training, whereas the other director was a business executive, relatively new to day care and people with dementia. It was clear that Florence understood the essence of people with dementia and their family caregivers. She expressed as much concern for my well-being as she did Bob's. Which resonated later when I learned that Florence's own mother suffered from Alzheimer's disease. As she explained the fee structure to me, Florence emphasized, several times, that if I should ever have difficulty paying the monthly fee, she would help me look for assistance. Her compassion touched me.

Florence was also wise—and firm. When we discussed transportation, I mentioned that Bob was still driving, and in fact had driven to our appointment that day. Florence made it clear that no one attending the day care center drove on their own, and gave me some transportation referrals. What also clinched the decision for me was Kate, the nurse/case manager who had recently completed a research project at the center and knew them well. She gave the center high marks, then jumped through hoops to pull Bob's enrollment paperwork together in a matter of days.

Throughout the process, Bob was cooperative as always, and entrusted me with the decisions. We began with a two-day program. Later, we moved to a three-day arrangement, and eventually five days a week, as Bob needed more help not only with keeping himself engaged with reading, puzzles or art, and staying alert, but also with daily routines such as getting lunch.

I still remember Bob's first day. When Bob's driver brought him home, I realized I'd had almost six hours of uninterrupted time to myself—something I had not experienced for some time. I got work done, was energized by the quiet time, and was able to engage with Bob more enthusiastically than ever, talking with him, asking about his day, and making plans for the rest of the day.

Over the years, it was clear that Bob enormously enjoyed his time at the day care center—chatting with people, watching people, and participating in current events discussions, exercise, art, and music. He especially enjoyed music—singing in groups, banging on drums, or just clapping along.

He also liked art, and I was the beneficiary of many of his art projects—cards on Valentine's Day and major holidays, and a soft pillow with a sticky note on it—To Lena. Love Bob—that I still keep in front of me in our family room.

Bob loved the food and the many treats he couldn't get at home—hearty sandwiches, french fries, and, oh, the ice cream socials that were a weekly treat. Yes, he was happy with his day care, but his enjoyment never overshadowed his appreciation for me. Whenever I arrived early to pick him up for a special outing or appointment, I would see him walking gleefully down the hallway toward me, escorted by a staff member, repeating excitedly, "Lena's here? Lena's here?"

Bob's physical and cognitive health were monitored by the attentive staff. Once in a while, a staff member would fact-check Bob's storytelling with me: "Did you really take him to see the solar eclipse?" Of course I did! It felt good to know they were engaging with Bob.

I would get an occasional call from the nurse, to tell me that Bob had a runny nose and ask if I could keep him home for a day or so. Or she might call to ask me if Bob had gotten his flu shot. Or it might be a reminder for me to send in updated health records as requested. I also appreciated the periodic phone calls from the director of the center to tell me how Bob was doing.

Over the years, I've also had occasion to recommend day care to friends or fellow support group members. I'd praise the benefits of social stimulation and a variety of activities, from guided conversations and art projects to music and exercise—a rich program that is hard to duplicate at home. And for the family caregiver, it's our respite time. Time we can count on to devote to ourselves, whether for work or pleasure, allowing us to resurface more energized to engage with our loved one.

Lena Chow Kuhar

Music Therapy

🔊 **Podcast Link**

Kristopher Hong, MT-BC, NMT

When I tell people I'm a music therapist, the first question people ask is, "What is music therapy? What do you do?" There's a misconception that a music therapist just plays or teaches music. While that can be part of it, our main role is using music as a tool to facilitate therapeutic processes. Our goals overlap those of physical, speech, occupational, and other therapists, and social workers—but using music as the form of therapy. I always say that we use music as the catalyst for healing.

Music is a universal language and, as such, there are few limits to the people it can reach. It can benefit people of all ages with a range of physical and mental capabilities. But it's especially beneficial to those with Alzheimer's disease, dementia, and other neurological conditions. This is the population that I work with—over the last few years, I've seen music therapy bring people out of their shells, and reawaken their spirit and liveliness. I've even had family members tell me they didn't know their loved ones enjoyed singing, but now they can be heard singing around the house!

Music therapy is grounded in research. Studies about music have shown how it helps facilitate neurogenesis, the regeneration and repair of neurons in the brain. Researchers have also found that music stimulates multiple parts of the brain at the same time, especially the areas affecting the five senses, language, and mood, as well as movement, balance, and gait. Music therapy has been shown to improve a patient's focus, communication, and memory. It also provides a safe, stimulating environment for socialization.

So you can imagine that music therapy helps us focus on different goals. In my work, though, I use it mainly to target our participants' cognitive and social skills. And while it benefits people at all stages of Alzheimer's, music therapy is especially effective in the middle and later stages when the individual becomes more disconnected from their surroundings.

In these later stages of the disease, when speech areas of the brain are often affected, people have more trouble communicating their thoughts. With music therapy the brain responds in conscious and subconscious ways we can't see. Often the reactions to music are immediate and visceral: The person may light up or show a different emotional affect. It can reawaken a person's interest in their surroundings and encourage movement. How many times have you found yourself tapping your foot to music or swaying back and forth? This is that subconscious reaction to the musical stimulus. The brain reacts before you even have a say in the matter!

The musical repertoire I select depends on the population and my therapeutic goals. Think back to the music you most connect with—it's probably songs you loved as a late teenager or young adult. According to research, the music you listened to from 18 to 25 promotes the most positive response. Since participants at our day care center are mostly geriatric, I draw from a playlist ranging from the 1920s all the way to the 1960s. Of course some folks prefer newer music, and some connect with music from their parents' era. We've had people in their 40s and then some in their early 100s, so that is a big span of time to choose from.

I choose the genre and tempo of music to meet my goals for that session or individual. For example, if someone is feeling stressed, anxious, or overwhelmed, I select sedating or calming music. On the other hand, to promote movement and exercise, I select an upbeat, stimulating song with a quicker tempo and strong percussion. A nice steady beat with prominent bass can help with gait training and balance.

At our day care center, I schedule morning and afternoon music groups, with smaller sessions in between.

The morning music groups focus more on movement and getting bodies and minds awake and alert. We pass out rhythm instruments and I lead participants in movements to a song, where I try to address all areas of the body. I start with the arms by playing the instruments in all directions, asking them to mirror me. I encourage foot-tapping and lower body movement with sit-down marching. I employ drum circles to get the arms moving, which also often turns into a cathartic, energy-filled experience.

The music therapy group in the afternoon focuses on a musical game or sing-along. I like using games like "Name that Tune" or "Guess the Musician." This works really well for stimulating memory and is fantastic for getting participants to start reminiscing—often prompting people to recount a story about times listening to the song in the past.

The sing-alongs may seem more straightforward, but I weave in therapeutic techniques to encourage participation, like having them sing verses back to me, echoing lyrics I sing, creating a musical round, or shouting specific lyrics. Under the guise of musical performance, I'm actually engaging many different parts of the brain.

Between the large morning and afternoon group sessions, I hold smaller songwriting and music appreciation groups, geared toward early- and early-middle-stage individuals. Our songwriting group is wonderfully creative. We rewrite lyrics to well-known melodies using our own narrative. Recently, we rewrote Sinatra's "Fly Me to the Moon" to become "Just Give Me a Spoon," about our love for ice cream. This fun, simple game helps accomplish three important goals: It engages the brain in a more cerebral way, helps boost self-esteem, and reduces depression and anxiety.

Since COVID-19 broke out, our entire program has become virtual. It has taken some tweaking, but it finally resembles the format of our in-person program. Despite the fact that it's not in person, I still see how beneficial our program is to our participants, their families, and their caregivers. I still see all the smiling faces when we break into song, and I still get to crack jokes with our participants. Plus, the caregivers still need respite, especially in these times when we are more confined to the house.

One of the beautiful things about music therapy is that it doesn't always feel like therapy. It can be presented as a fun drum circle or musical game while therapeutic techniques are cleverly woven in. Our sessions are meant to be fun and engaging without the need for explanation. Music therapists are really blessed in that our tools are inherently enjoyable. We don't have to force our therapy because most everyone already loves music. It's one of the great natural motivators.

Through my time serving people at our day care center, I've been fortunate enough to see the difference that we can make. It reminds me that not only is this beneficial to our participants, but also to me. I'm grateful that I can make a difference while also learning and growing with these individuals. It makes me proud to say that I am a music therapist.

Kristopher Hong, MT-BC, NMT

Program Coordinator/Music Therapist
Peninsula Volunteers Inc.
Rosener House Adult Day Services

Honoring Loved Ones Through Art

🔊 Podcast Link

Katherine Diane Brandt

When my son, Noah, was in fourth grade, he made a sculpture in art class. He worked on it for weeks, giving me frequent updates on the different stages of working with clay and waiting patiently for his turn at the kiln. When I asked what he was sculpting, Noah only replied, “You’ll see when it’s ready.”

The big reveal came on the night of the Spring Art Show. The school was alive with chatting parents and proud kids eager to show off their creativity. We wound our way through tables of paintings, jewelry, and crafts, each encircled by a posse of fans exclaiming, “I love it!” or “How did you come up with this?” I was reminded how love has the power to raise even a simple school project to the level of high art.

We arrived at a long table where a dozen little figures sat shining under the display lights. They were, as Noah explained, Pueblo storytellers, showing the tradition of passing wisdom from generation to generation. I knew Noah’s sculpture right away. It was an adult figure, his mouth rounded in the circle of a storyteller, holding a smiling child figure in his lap. “It’s me and Dad,” he said. I hugged Noah quickly to hide my tears. Grief is like that sometimes. So sneaky, and so close. “It’s perfect,” I said. “Dad would’ve loved it.” Noah went on to say he’d also wanted to make a sculpture of our two cats, but didn’t have time. The missing cats were a welcome distraction from what was really missing.

His father had passed away six years before this sculpture was crafted, at the age of 33. In the years before his passing, Mike lived with frontotemporal dementia, or FTD. He could not tell Noah stories, or hold him in his lap.

I saw that Noah's art was an expression of his longing, a way to connect with his dad. I wondered whether Noah remembered another time his creativity built a bridge to bring them together.

In the early, mild stage of Mike's dementia, the idea of art enrichment didn't come up. As our lives unraveled at an overwhelming speed, each day felt like chaos. But when Mike progressed into moderate-stage dementia, I began looking for ways to give his days more purpose. He became a participant in a local adult day program, which gave me respite while offering Mike care, social connections, engagement with music, and exposure to art.

My hope was that art might be an enjoyable way for Mike to grasp his experience. But my expectations were too high. As it turned out, Mike was less interested in making art than putting art supplies in his mouth to explore their texture with his tongue. Rather than battle with Mike, the staff took him on walks with a therapy dog during art time. I was happy to sacrifice the joy of seeing Mike's art for less worry over him swallowing paint.

As time passed, and Mike's brain succumbed to the devastation of FTD, he needed more help in his daily activities. He was unable to meaningfully answer questions about himself or take part in conversations.

I made the difficult decision to move him to a local skilled nursing facility.

With a young child to raise, I couldn't see Mike every day.

Thinking about Mike without me, surrounded by people who didn't know him, I decided it was critically important that I fill in the blanks with more than just the facts, so people around him would know his story. The data in his resident profile couldn't begin to convey all the beautiful things that made Mike Mike.

In college, Mike was known as "Big Mike." True, he was tall and broad, but it was his warm and outgoing personality that earned him the nickname. People who knew and loved Mike often commented on how engaging and gregarious he was. His easy laugh. His enthusiasm for talking and connecting with others. Mike spoke openly about how much he loved me, and how excited he was that we would become parents together.

I wanted people stepping into Mike's space to connect with this vibrancy. I wanted people to see that Mike was more than his dementia. I wanted them to connect with him as a father, a husband, a son, and a friend. To see him as a whole person, despite all that he had lost. When Mike could no longer use his voice to communicate, we needed a new medium to show who he was without speaking a word.

I do not consider myself an artist. I love photography and have taken classes, spending hours in a darkroom. One of Mike's last gifts to me, the month before Noah was born, was a Nikon D40 digital camera. This became my medium for telling Mike's story.

Of course, Noah was the star. I decorated the walls of Mike's room with poster-sized snapshots, each one capturing a moment in Noah's life. Beautiful portraits of Noah exploring a hermit crab on the beach, beaming with mischief after a run through the sprinklers or with quiet concentration as he hung an ornament on the Christmas tree.

Noah expanded on the photographs by creating elaborate collages with glitter, stickers, and markers. I painted his bare toddler feet and let him walk across each masterpiece, a stamp in time to mark the moment.

It brought me comfort to know that no matter where Mike looked in his room, he would see reminders of our love story and the little life we created together.

So many years after he sculpted it, Noah's art project had become much more than just an art project. And even more than an expression of his grief, Noah's work touched on how the ability to tell our story is central to our personhood. The photos and toddler collages told Mike's story. They were as critical to Mike's well-being as his care plan.

I know that this desire is shared by many people with dementia and their caregivers, who can take the same route I did, using a creative medium to convey the importance of a whole person and a life lived.

For the person with dementia, it can take the form of a new skill, adapted to any stage of the disease, or an iteration of a lifelong endeavor. Either way, art offers the opportunity for creation even while experiencing loss.

During Mike's care, it was important for me to hear his voice through my expression of his story. Today, it is important to Noah.

It's been eight years since Mike's passing, and two years since Noah created his sculpture. He has grown into a precocious middle-schooler. In 2019, he was invited to participate in a patient and caregiver art exhibit and gala fundraiser to benefit the Massachusetts General Hospital Frontotemporal

Disorders Unit. The evening featured live music, scientific talks, and lots of dancing. The art exhibit honored Featured Artists, individuals whose lives were touched by dementia.

Noah submitted *Storyteller* as his signature piece. I watched from afar as Noah stood beside his sculpture. He looked tall to me, and confident, wearing his first tuxedo. I thought of him creating the sculpture, shaping each face and hand, carefully placing the child on the parent's lap, ready and alert for what would come next.

I watched Noah greet each guest and answer questions about how his dad inspired this work. Noah had become the storyteller. And through art, he was honoring Mike's life. It was probably not his intention when he made the sculpture, but it was proof that a connection from the past had found a way to our present, keeping the stories alive.

Katherine Diane Brandt

Director of Caregiver Support Services and Public Relations
Massachusetts General Hospital Frontotemporal Disorders Unit
www.loveisoutthereftd.org
www.ftd-boston.org

Links

PODCASTS ON LIVING WELL

Self-Care for the Caregiver
After Diagnosis: Lifestyle Practices
Choosing Kindness
I Repeat—Coping with Repetitive Behavior
Conversations
Cognitive Fitness
Still Bob
Day Care
Music Therapy
Honoring Loved Ones Through Art

LISTEN ON YOUR FAVORITE PLATFORM

Apple Podcasts
Google Podcasts
Spotify
Stitcher
YouTube

FOLLOW US @BOBSMARATHON

Facebook
Twitter
Instagram

WEBSITE

bobsmarathon.com

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."

ISBN 978-1-7375812-1-5

10-minute podcasts available on
Apple Podcasts, Google Podcasts, Spotify,
Stitcher, YouTube, and our website.

bobsmarathon.com