



## TRANSCRIPT

# Family

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

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

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

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

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

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

decline, especially around feeding and hygiene, would raise even more barriers to his relationship with his children. It was up to me, sometimes with the help of a home care person, to set the stage for visits that were filled with joy, not fear.

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

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

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

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

Lena Chow Kuhar