Peter & Barbara Black speaking at the Senior Lecture Series, a program under Hawaii County's Kamana Senior programs, January 6, 2026

Peter Black spoke briefly and his notes do not survive.

Barbara Black:

My perspective on Alzheimer's, and Peter's in particular, is that of a caregiver. We are very lucky in many ways—one such gift is that we have always communicated clearly, directly, and openly. And that is carrying us through this experience. So far. And Peter's character and personality is also a gift.

Since Peter was diagnosed in 2015, we have had the luxury of time—time to plan how we would manage this terrible disease. Time to learn more about it, and time for me to learn about caregiving. Strong support from friends and family is another gift to us both.

Caregiving for a spouse with Alzheimer's is complex and difficult. It can be very hard—to find time, to focus, to remain patient and calm. Peter has changed—he can be very bossy to me lately. He has shown evidence of a strong temper, a new phenomenon, toward me.

Every day seems to present new challenges as we both change. I manage Peter's medications for him; I manage our bills, and he looks to me for help with all kinds of things: the GD phone, computer, hot water.

On the other hand, Peter is determined to continue to do what he always has done—all aspects of laundry; making 3 meals a day for us; managing the kitchen; and light housekeeping.

One thing that is hard for me to remember is that this disease takes away the ability to learn new things. For example, there is no hot water, Peter says most every day. He has forgotten where the faucet needs to point for hot water. Each time I show him and he says "oh, ok." But it doesn't take. As he puts it, it is in his brain somewhere, but he cannot retrieve it.

- I try always to say yes to Peter, unless it is a safety issue or otherwise a bad idea. And he is a fountain of ideas. Most mornings, when I wake up, Peter greets me with “I have an idea.”
- I try to help with whatever he needs or wants.
- I try never to say, “don’t you remember?”
- When I must let him know he made a mistake (his word), I try to be gentle because, as he points out, he is very fragile.

Our relationship is strong and we continue to communicate clearly. There has been no denial here in this journey. We talk about our relationship—what is going on and how we can keep it strong and true. I know this will become more difficult over time. The progression of this disease is not positive.

We have always been interested in brains and cognition in all its many aspects. The nature of memory. Consciousness. All the metaphysical questions about who and what we are. And we are learning a lot. Have you heard of simultanagnosia? We call it seeing and not seeing. Peter will lose his phone, and I will say have you looked at your bedside table? Yes, I have, he replies. I will look at that table and there is his phone! This happens a lot. It is basically a perceptual issue.

Since I need all the help I can get, I sign up for as many trials and studies as I can and I have learned some valuable things. From elephants and rabbits to remembering and using my core values to influence my responses to daily life. I have learned how best to turn the lens—a metaphor that helps me a lot. I joined a support group—something I have always avoided—and I have found it wonderful and valuable.

I do want to stress the difficulty and expense involved when patients on Hawaii’s neighbor islands, need to fly to Oahu for medical care. Many people simply cannot afford all the costs involved. We travel to Oahu every other week for Peter’s Leqembi infusions at the Pali Momi Cancer Center’s infusion center. Not all insurance (including ours) pays for that travel.

On the other hand, I want to mention that once we walk into the infusion center, we feel completely at home, welcomed and cared for by the amazing nurses, aides, and other staff. The infusion itself is a completely benign experience—an IV is started and after an hour or two, Peter stands

up and we head back to the airport. No serious side effects so far—unlike chemo.

I will end by saying that our philosophy of life is expressed most clearly in Verna's "If can, can. If no can, no can."

A final note: Alzheimer's and related dementias cost Hawaii's Medicaid program $285 million. It primarily affects older adults and in Hawaii, about 20 percent of residents are 65 and older. Early detection and planning can help mitigate these costs through timely intervention, better care planning, and access to treatments that can slow the disease's progression. Much research continues and new treatments are rapidly becoming available. We encourage everyone to ask for the brief cognitive assessment in their Medicare wellness visit.