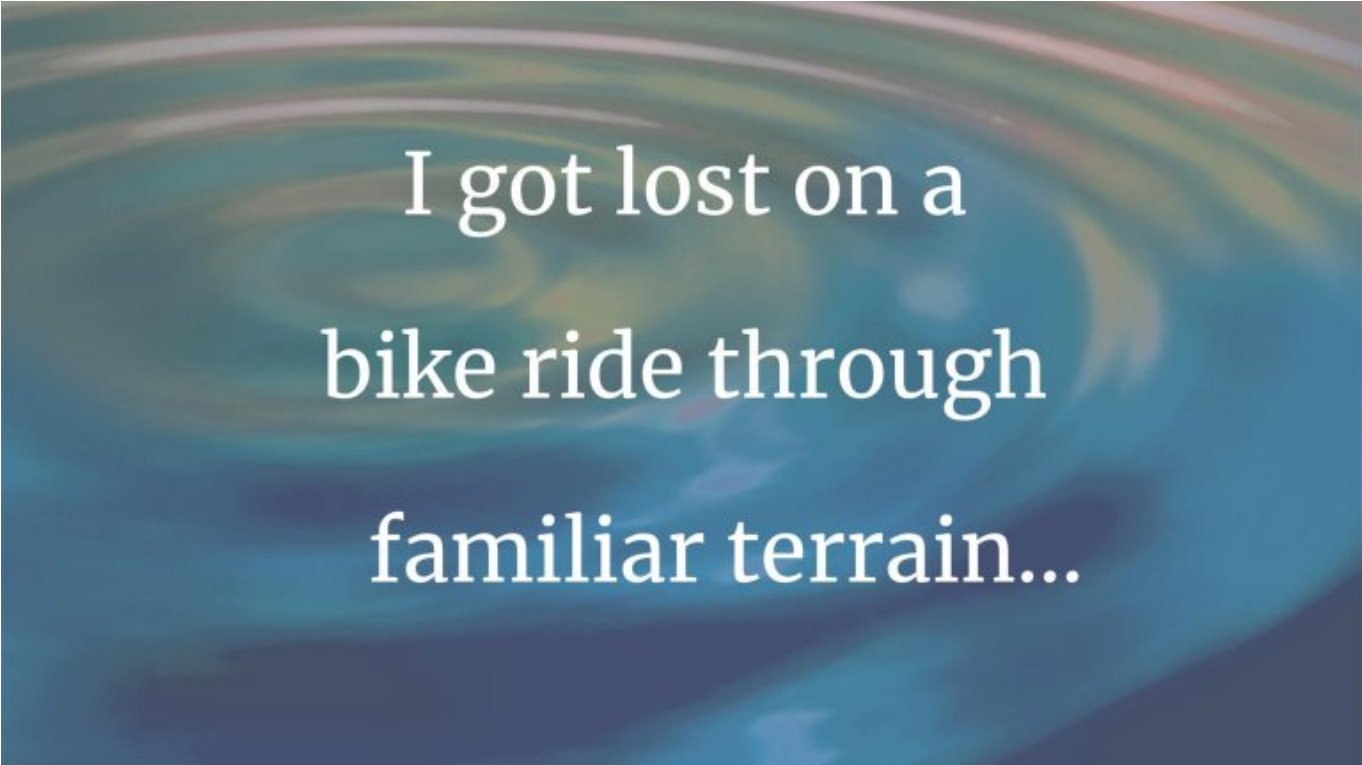


My Alzheimer's Story

Category: Stories

written by Lisa Burr | May 26, 2023



I got lost on a
bike ride through
familiar terrain...

My name is Lisa Burr. I am a family nurse practitioner, and have been for nearly three decades. I grew up in California, the "Sunshine State."

In the 1960s, my dad, a military test pilot, was the first astronaut with NASA's Manned Orbiting Laboratory (MOL) program, which pioneered crewed space stations as reconnaissance satellites. My mother was a beautiful model.

Dad's mother had died early from brain cancer, and he attended a military academy school. Dad was very strict, and my two brothers and I had to eat at the table military-style—put food on your fork, lift it straight up to mouth level, eat and don't talk! Yet he also taught me math and science, including how to use a slide rule to measure distance and speed.

We moved often, and each time I would have to leave my friends. When I was college, I took the GRE and scored in the top ten percentile. My friends said I had a "hard-drive" brain.

I knew early on that I wanted to become a nurse. I could help people, and I thought it would be an interesting and rewarding career. I attended nursing school at the University of New Mexico and graduated with my bachelor's degree in nursing in 1985.

My husband, Mark, an ER physician, and I met in 1989 in Austin, TX, where we had both moved from different states. We worked together in the ER for several years. We each had our own ideas about the proper approach for our patients, which led to some lively discussions, but ultimately benefited the

patients.

In 1995, after receiving my family nurse practitioner's degree, I began a job on the east side of Austin, in a clinic for the working poor. I loved working with the Hispanic families, with their gracious *cortesía*, and I enjoyed making home visits to my patients.

During these years our children were born: Sam, who is in medical school in Austin; Grace, who lives in New York City and works in finance; and Matthew, who is doing well in finance and commercial real estate in Dallas. My mom and dad (both of whom have now passed, unfortunately) were wonderful grandparents to them when the kids were growing up.

In 2018, Mark developed a rare type of leukemia and needed a stem-cell transplant. A nurse in Houston looked in the universal registry and found a match with a Greek man, whose stem cells were sent for the transplant. Our kids were so worried! Fortunately, the transplant was successful.

I took care of my husband intensely during this period. It was about this time that I started suffering from short-term memory loss. I got lost on a bike ride through familiar terrain, and after twenty-eight years as a nurse practitioner, I began having difficulty with numbers. I was not confident with drug calculations, so in 2019 I had to step back from the work I loved.

I felt so aimless.

At about the same time as I started having memory problems, I was diagnosed with autoimmune hepatitis. After several ineffective treatments, I received ten rounds of cyclophosphamide, and my hepatitis is now in remission. We initially thought that the same process that was injuring my liver might also be affecting my brain; however, this did not prove to be the case.

After three years, I finally was able to get into the Mayo Clinic in Rochester, MN, where I had a PET/CT scan and MRI of my brain, as well as a lumbar puncture. These tests clinched the diagnosis of early-onset Alzheimer's disease.

My neurologist at the Mayo was a bright, kind and thoughtful man.

He explained the outcome of the tests as gently as he could. I was, honestly, devastated. *Why me? Why this diagnosis?*

Even harder than hearing this news was communicating it to my children, all in their twenties. So many tears.

Then they all rallied around me. They held me tight. They were strong.

In November of last year, shortly after my diagnosis, my daughter Grace and her friends set up an Alzheimer's walk at the Circuit of Americas in Austin. My friends and family were all there. We raised \$35,000 for Alzheimer's research!

Grace also made a poster of the Alzheimer's-disease process inside the brain,

showing nerve-cell injuries including tau tangles and beta-amyloid plaques. The injury to the brain leads to progressive problems with memory, thinking and, in my case, tasks that require sequential steps to complete.

For example, I have great difficulty with calculations—leaving tips, counting change or following recipes. I used to work a lot in my garden, and I still putter and keep things neat, but I find it very difficult to plan and create a flowerbed. If I go on a bicycle ride or long walk, I need to keep my phone map up so I won't get lost.

I used to know everybody's names; my husband would text me and describe someone he'd run into at the store, and I would tell him who he was talking to. Now I have to keep a list of neighbors' names so that I can remember who they are.

I've left my credit card at the store a couple of times, so I have to be very careful about those transactions. And I'm unable to plan trips or vacations at all. I used to be the manager of our trips, but I've had to turn this role over to my husband.

I am considered to have moderate dementia. I realize that I likely will not be cured, but I still feel hopeful about the new possible treatments. For instance, lacanemab has shown promise with early Alzheimer's, but has a risk of brain swelling and other side effects. I am planning to enter a clinical trial in hopes of ultimately helping others who have Alzheimer's.

I also plan on getting genetic testing soon, as I worry a lot that my adult children may have inherited a genetic predisposition to early-onset Alzheimer's. This may be my most terrifying fear about this whole process.

Meanwhile, life goes on, with much to enjoy. I am an avid runner and bike rider, and last February I did a half marathon with a good friend whose parents were also in the aerospace program. I am volunteering at a homeless shelter. My husband and I are coming up on our thirtieth anniversary. Our relationship is strong.

I am richly blessed in many ways. I remain hopeful.

If the Alzheimer's researchers do not find a cure in time, I will ask my family to spread my ashes over Ladybird Lake, near Austin, after I pass.

I am fifty-nine years old.