

Landing in Afghanistan

Someone once compared having a disabled child to landing in a different country than originally planned. Your dreams and guidebooks were for Italy and all its treasures, and Holland, though beautiful, was not what you wanted. You had waited your whole life to see this ancient country with its art and monuments and passionate gesticulating people, and your plans were inexplicably ruined.

You were planning your life with a normal child, and your actual child was not what you expected, and life would be different. Your heart would rip open beyond what you thought was possible. The plane landed in Holland, a country that you had no interest in going to, but if you opened your eyes and accepted this new world its beauty would be revealed. I liked the analogy. It had been faxed to me by our hospital social worker when Lueza was an infant and it had become clear that she had sustained a brain injury at birth that wasn't magically disappearing, as I had hoped. The plasticity of the brain wasn't working out. A catastrophic accident had occurred. There had been a cosmic mistake. God had chosen the wrong person for this test. I was too weak to cope. Because I was so weak and hysterical, Lueza would have to be okay. This was as clear as I could figure it out. I believed in this rule. Only strong people could survive something like this. Lueza would be fine. This reasoning kept me walking and talking when I longed to drop to the floor and writhe and rend my garments.

Holland was a gentle place in my mind. I knew that they had a high percentage of home births. It was filled with Rembrandts and the sacred memory of Anne Frank. They could all speak English.

I wanted to write my version of this unexpected landing. We had not arrived in Western Europe. There were no tulips. No English was spoken. It was on the other side of the planet from where we were hoping to go. Terrorists had stolen our plane. We had crash-landed in Afghanistan. Our daughter had barely survived the landing. Her brain was exploding with seizures. Babies were dying. Mothers would arrive at the NICU and be told that their tiny premature babies would not survive. We wore yellow paper hospital robes and held Lueza, who slept for six days flooded with phenobarbital to protect her from more seizures. They gave us rocking chairs between the clear plastic isolates so I could try and nurse. She was nourished with my breast milk through a feeding tube in her nose. Her seizures became almost invisible, but then a little gray ashy color would spread around her mouth and she was seizing again. I thought Lueza was dying. Yelling from me brought nurses who explained that it was not death. Her brain was just convulsing, and because she was so sedated with barbiturates all that showed was a lowering of oxygen in her face.

Holland couldn't be this terrifying. This was a dystopia. Birth and near death. Baby rushed into territory of hospital with other doomed babies. Giant radioactive machines being wheeled around close to babies. Babies who were see-through and not quite finished. Eyes taped shut. Sporting hand-knit volunteer-donated wool caps to maintain their body heat. Incomprehensible language being spoken. No guidebooks for Afghanistan. War unending. You could die of exposure in the frozen mountains. A terrorist could blow you up. Only way in was by warplane or a crash landing.

But the people were famous for their hospitality. They would share their last cup of tea. The beauty of the land was extreme. People lived there and raised families. The love was fierce. Someday I thought, I would write my version of Lueza's early days and how it was.

It is hard to breathe when I remember this time.