

FIELD NOTES | SPRING 2023

The Man Across From Me

By John Pierce

The man sitting across from me has ALS. His colorful shirt cannot hide the hollow spaces at his temples or the prominent tendons of his hands. I watch the woman sitting in a wheelchair at the end of our row. She also had ALS. A foam collar holds up her head, something her neck can no longer do. Her arms dangle uselessly as she sips water from a straw her husband holds. Yes, all of the patients in this waiting room have ALS.

ALS is easier to say than amyotrophic lateral sclerosis, a relentless disease with a life expectancy of three to five years. ALS victims lose the ability to walk, to hold up their head, and eventually to swallow and talk. My neurologist had spoken those three letters eight weeks before, pronouncing a terrifying diagnosis portending my relentless path of disability and suffering. Soon, others would feed me, toilet me, a machine would talk for me. I would lose my independence, become an enormous burden on my family. It was the worst possible fate. How could a loving God possibly let this happen?

My neurologist encouraged me to get a second opinion. Thus I traveled 400 miles to a national ALS center, where I saw an expert who confirmed my diagnosis. He suggested that I return today to discuss enrolling in a clinical trial that might advance the scientific understanding of ALS. So now I sat in this awkward space, surrounded by others with whom I shared a terrible diagnosis, observing the frightful vision of my future.

The man sitting across from me was reading a Bible – leather cover, ribbon bookmark, text printed in red to emphasize the words of the Savior. "A book of comfort," my eighth grade Sunday School teacher had called it. As a questioning 13-year-old, I chaffed at religious platitudes. There was a lot in the Bible which wasn't so comforting: an angry teenager who murdered his brother; 20,000 people enslaved and abducted to a foreign country; a young preacher whose compassionate teachings ended in execution, nailed to a cross and left to die of suffocation and exposure.

Without looking up, the man spoke. His voice was slow and breathy, so soft that I wasn't sure if he was talking to himself or to me. With uneven cadence and poorly articulated velar consonants, it almost sounded as if he was speaking a pidgin language.

"The disciples saw a blind man and asked Jesus if the man was blind because he had been sinful or because his parents had been sinful. And Jesus told them, blindness doesn't come from sinfulness." The man paused to catch his breath, "Now I'd agree with that."

I pretended that I wasn't listening. But he went on. "Then Jesus shouted 'No! This man is blind in order to show the glory of God!" He paused again, and made a chortling sound, as if trying to clear his throat, or perhaps to chuckle. "That's a hell of an answer don't you think? How can having a terrible illness, like blindness, or say ALS, possibly show the glory of God?"

I was familiar with this passage from the book of John, where Jesus then mixes his spittle with mud and cures the blindness. But the man across from me stopped short of the cure. I looked up. He was staring at me.

"When I was diagnosed with ALS, I worried that everything I valued would be taken from me. How was I going to ask someone to feed me or put me to bed? I became paralyzed, not by ALS, but by fear." He paused. "But after a while, I thought maybe I needed to start thinking about God instead of pitying myself." He looked away and added, "So I decided to sign up for a clinical trial. I wasn't hoping for a miracle cure, none of these trials offer that. But I thought that doing something that might help a future ALS victim would turn my focus outward instead of inward, to think about others instead of me. And maybe that would be a way to show the glory of God."

I dislike unsolicited advice, especially from strangers. And I certainly didn't need any more fear. But this man wasn't offering advice and didn't talk of fear. He spoke instead of the joy and comfort that he felt when, despite a terrible illness, he reached beyond himself to help someone else and to serve God. He spoke not of a medical cure, but a spiritual one.

Despite the bizarre nature of this uninvited, intimate encounter with a total stranger, I found myself feeling cheerful and less anxious. For the first time in many weeks, I felt an unexpected optimism. Yes, I thought, it would be liberating to look past my own anxieties and help someone else. That's something I can do. And maybe that would lead me to a God of comfort and hope.

A nurse called my name. As she ushered me from the waiting room, she said, "I understand you might be interested in a clinical trial." I looked back and glimpsed for the last time, this stranger in a colorful shirt whose unbidden witness would change my life. He smiled at me, nodded almost imperceptibly, and closed his Bible.

Dr. Pierce practiced in West Texas as a primary care internist for two decades, and then served on the faculties at the Texas Tech University School of Medicine and University of New Mexico School of Medicine (UNM). He retired from UNM in 2018 as Professor Emeritus. Some of his narratives have been published in The American Journal of Medicine, Annals of Internal Medicine and the Journal of Graduate Medical Education. His journey with ALS has been characterized by an unexplained arrest of symptoms.