

Elephants: Another Day with CFS

Category: Stories

written by Linda Koebner | July 12, 2019

Linda Koebner ~

Two elephants won't leave me alone.

Every morning, as I struggle into consciousness, my brain makes plans. *I will get up out of bed, go pee, find my way to the kitchen, put water on to boil, fit the paper into the coffee filter, grind beans, slow-pour over the grinds...*

In my mind's eye, I visualize that the coffee is hot, that the news I read is upsetting and that, caffeinated and dressed, I am up and into my day. My thoughts take me out the front door for a long walk with my dogs, and then to work.

The reality is that I haven't moved a muscle.

The elephants have trapped me. Every night, for twenty-nine years, these two have come to sit on me. They somehow manage to lumber past the dogs, who sleep on without a bark or snarl. The elephants climb up into my bed without disturbing the cat curled against my legs.

How can two 6,000-pound elephants with monstrous feet, ears as big as tents and trunks as long as my dining-room table sneak in without being noticed? Why do they arrive at 4:44 am without fail? Why do they sit on me, rousing me and keeping me awake for hours until their weight lulls me back to sleep, just in time for my alarm to ring? How do they find their way not just onto my body but *into* it? Their weight moves down through my arms, legs, hands and feet, making it impossible to move. I feel nauseous and panicky. *Maybe they'll never leave, I think desperately. What do they want?*

Some days, I speak to them.

"You've made a mistake," I say.

Surely they have the wrong person. The woman I am has a family, a career, a life: She gets up and goes. The woman the elephants sit on is squashed and helpless. They must have the wrong address.

"You must stop visiting," I tell them.

We have this conversation every day. I beg, I cajole, I barter, I cry, I offer them the best bananas, caresses behind their ears—anything, if only they'll go away.

By the light of day, my affliction goes by a different name: chronic fatigue syndrome (CFS).

But after years of struggling to describe this poorly understood malady to others, I finally settled on calling it my "elephants." I thought this might help people to imagine it more clearly. And admiring elephants as I do, I find it a friendlier term. For more than thirty years, I spent my

professional life with exotic animals (primarily chimpanzees), and I've come to know several elephants personally. I've felt the immense pleasure/sadness of bottle-feeding orphaned baby elephants—one fell asleep with her head on my lap. So I'm not afraid of elephants; but when one sits on you, it's impossible to move.

I probably had this ailment even as a young girl. As long as I can remember, I've suffered from diffuse malaise, fatigue and random pains that my family called "Disease X." I function well enough; I made it through high school, college, global adventures and a professional life, and I raised a fantastic son. But I've never felt well, or interacted with the world as I imagine other people do.

The elephants first officially visited me one January morning in 1990. My son and I were in Lake Placid, NY, for his figure-skating competition. Rising before dawn to wake him, I felt like I had the flu. But this "flu" didn't run its course. Back at work in New York City, I took my four allotted sick days. Days turned into months and years as I struggled on with a low-grade fever, swollen glands, gastrointestinal distress, brain fog, sore throat, excruciating headaches and sleeplessness. Every cell was exhausted, but I couldn't sleep—and if I did, I woke up more tired than before I went to bed. Of course, as a middle-class, insured person, I saw every medical professional imaginable. Hearing that I'd spent decades in the company of chimpanzees and other primates, my doctors appeared delighted to search for a parasite to blame. Stool sample after blood test turned up nothing.

"It's surely depression," said my very pedigreed physician. He put me on a sky-high dose of Prozac that brought me close to suicide. I saw nutritionists, sought out every remedy of Eastern or Western medicine, underwent diagnostic procedures from HIV tests to brain scans to bone-marrow tests and endured the profound anxiety of waiting for the results. Always negative. Every measure equaled perfect health. I was certain that I was dying, and soon; I just wasn't certain of what.

After two years of this, someone told me, "The tests are making you sick." I stopped searching, because it was true—how much contrast dye and barium can a body hold?—and because I lost my job, and my medical coverage. I enrolled in an NIH-funded study. *At least my body can contribute to the understanding of my ailment(s),* I thought. *And if there are answers, perhaps I'll be among the first to know.*

In the years since, my symptoms have continued. They ebb and flow. I try diets, medications, meditation, exercise, no exercise. Like the elephants, the symptoms are my companions through life. I have learned to manage them, more or less. In many ways, they've directed me to live life as fully as possible. To embrace my work, my friendships, my family—and now, especially, the chance to spend precious time with my grandsons.

I seek medical advice as needed, or as new research emerges.

There's been one especially important breakthrough: Nowadays, most physicians understand that this is not just in my head. The NIH supports research (though not enough) for the estimated 836,000 to 2.5 million Americans who've been diagnosed. I feel heard, and no longer alone.

My symptoms can be mild or strong, and they shift from one body part to

another. But for twenty-nine years, one thing has stayed constant: Every morning, as my mind emerges from sleep, the elephants come to visit.

I never know how long they will stay. Their visit starts at 4:44 am (a glance at the clock confirms what I already know), but when they'll leave is unpredictable. *Is it based on my physical or mental state? I wonder. My sleep cycle? Or do they have someone else to visit after me?*

I don't know why they eventually let me rise. Sometimes, even after they've released me, a trunk will wrap around my leg and pull me back down, as I seethe: *Why do you play with me this way? Do you find it funny?* Finally, with what I imagine as an elephantine chuckle, they let me go.

I get up, weak and a bit dizzy, to make coffee, read the news and get on with my routine. The elephants leave behind traces: Bits of hay in my ears give me a headache, the lingering odor of their bodies causes brain fog, pain stabs my legs where their tails have poked me. Pushing at their rumps as they heave their immense weight off of my body leaves me tired. But they're gone!

Inwardly, I feel enraged and helpless. I know they'll be back. I fear it. Yet, as long as they don't stay forever, I'm also grateful: Their absence reminds me how horrible it would be if they stayed for good.

Contemplating that possibility, I feel lucky to have *these* elephants, who are kind enough to let me be after a few hours. They've been my companions for so long; I know them well. If they vanished, though, I wouldn't miss them. Every night, I hope that they'll forget to visit.

But then, as we all know, elephants never forget.

About the author:

Linda Koebner, a lifelong advocate for animal welfare, is founding executive director of the NIH's chimpanzee sanctuary system, a haven for chimpanzees retired from biomedical research. Her work has been profiled by the BBC and on the PBS program *Nature*. This is her second Pulse story, and she has written many books, including [Zoo Book](#), [From Cage to Freedom](#) and [For Kids Who Love Animals](#). After earning a master's degree in health advocacy from Sarah Lawrence College, she helped to initiate a pet-therapy program for hospice patients at Montefiore Medical Center, in the Bronx. "Writing has always brought me comfort and leaves me amazed at what appears on the paper if I just let go. I so admire *Pulse* for providing a forum for the stories of our complex medical world. After decades of hearing people say 'But you don't look sick,' I was finally ready to tell my story of living with this misunderstood ailment. I hope it may help others feel less alone with their pain and confusion. Even if we don't yet have the answers about CFS, perhaps the elephants can do *something* helpful by sharing the impact their weight can have on a human body."

Story editor:

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