

Living on the Edge

Category: Stories

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Adapting to a risky new diagnosis...

"How are you adapting to your diagnosis?" the specialist asked. "What changes have you made in your daily life?"

"I take the phone with me to the barn," I told her. "That way if I need help I can call."

She looked at me gently, as one might regard a confused child. Even then, I didn't expect the heavy blade of her answer:

"There wouldn't be time."

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My life changed in 2017. My husband and I had raised our family on a small Ohio homestead where we tended chickens, bees and dairy cattle. Our daughter, who'd handled all milking and mucking duties, had moved into her own home, and we'd come to the end of our cattle-raising days. My husband's back problems made heavy work difficult, and I couldn't manage some large-livestock chores.

Still, our empty pastures made me sad. We'd recently become grandparents, and I wanted our grandchildren to grow up helping to care for and enjoy farm animals.

The problem was solved when I learned about a small, hardy breed of sheep called Babydoll Southdown. I eagerly put a down payment on a herd. There was one complication: Neither my husband nor I knew how to shear sheep. So we

signed up for a weekend workshop—the first time we two had gone away together in over fifteen years. Of course, a sheep-shearing vacation!

We drove to the remote farm, pulled on overalls and boots, then joined the class in a barn. After a lecture and demonstration, we were told to get started. The animal has to be tipped back, spine between the shearer's legs, the shearer leaning down to cut broad swaths of wool. I'm a little over five feet tall, and the sheep seemed huge. No one else appeared to have difficulty holding the animal in place while bent over, but pain began spreading from my neck to the back of my head. At first I thought I'd strained a muscle. Then I knew I couldn't continue.

I found my husband, off in the left-handers' area.

"I'm not feeling well," I said, then reminded him that we'd paid hefty fees for the workshop. "I'll be fine in a few minutes," I said. "You go ahead."

Instead, he took me to the hospital. I was admitted and, over the next few days, diagnosed with a heart problem, two inoperable brain aneurysms and a rare disease called fibromuscular dysplasia (FMD), characterized by progressive twisting of blood vessels throughout the body. A carotid artery tear, due to FMD, had caused my neck pain.

My diagnoses meant a vastly heightened risk of a brain bleed. This might happen soon, or not for thirty years. A few weeks after being discharged, I messaged my neurologist asking about what I hoped was a transitory problem. He messaged back that with FMD I could expect "focal neurologic deficits." I looked up that term. It included such things as numbness, loss of fine motor control, aphasia, even paralysis.

At my next appointment I asked my neurologist if it was safe to continue living in a rural area where our volunteer ambulance crew couldn't respond quickly to emergencies. He hinted that I'd be better off in an urban area where specially designed stroke ambulances were available.

But, he said reassuringly, "I wouldn't be surprised if you make it well into your eighties."

I let out a sigh of relief before another question arose: "What's the likelihood I can live that long without brain damage?"

He declined to speculate.

There are no cures. There's little that medical science can do other than prescribe blood thinners and warn against strain. I was given a strict weight limit of fifteen pounds. I was told not to push heavy doors, shovel snow, dig in the garden, pull on a dog's leash, carry heavy grocery bags, do a single sit-up. I was warned to avoid anything that might whip my head around—no horseback riding, powerboats, snowmobiles, motorcycles, amusement-park rides or (obviously) car accidents. Also, no chiropractic adjustments or massages—and I should avoid tipping my head back to have my hair washed in a beauty salon.

When I asked about sex, my specialist said, with a Church Lady face, "I wouldn't advise a patient about such a personal choice."

I didn't cry at any of my doctor's appointments. Didn't cry when I told my children. I mostly felt shock and outrage.

What life lesson is this? I wondered. *Am I deficient in gratitude? Have I run out of good I can do for others?*

But I didn't want to waste too much time on self-recrimination, especially since time might be less abundant than I'd imagined a woman in her fifties could expect.

Feeling generous amounts of fury, I gave up the flock of sheep we'd put a down payment on; my husband was sure they'd cause me to overexert. No more lugging piles of books to the library sale, no more helping an elder rise from her chair. I'd need assistance with gardening tasks like digging, dragging the hose, collecting the harvest. Even cooking would require planning, for everything from hauling in our food co-op order to lifting the KitchenAid mixer from the cupboard. (It, too, weighs more than fifteen pounds.)

What *did* make me cry was how I couldn't be fully engaged with my grandchildren. No picking up kids to put them in a highchair, to dance around the kitchen, to set them in tree branches so they could pretend to be birds. No plopping them in wheelbarrows for a ride back from the barn. No whirling them up in the air for games of bulldozer and crane. No lifting them onto my lap for a snuggle. I cried about this a lot.

The risk of a sudden brain bleed hung over me most heavily when I didn't feel well. The symptoms I'd had for years—dizziness, headaches, neck pain, palpitations, heat intolerance, feeling faint—now had an all-too-ominous explanation.

But we humans adapt. Sometimes this is a curse: We put up with a bad job because it's easier to complain than find a new one. Sometimes adaptation is a blessing: Newborn babies keep us up at night, and somehow we manage to zombie-walk for a few months until they finally start sleeping more.

Unbidden, I found myself reconsidering my activities from the *What-if-I-dropped-over?* angle. If I felt awful in the shower, I didn't want to be naked when found, so I'd dry off quickly and try to dress, realizing with a snort of laughter that it takes more exertion to get pants on over not-quite-dry flesh. If I went out for the mail, I didn't leave a pot on the stove, in case I perished before getting back in, and set the house on fire.

These weren't constant preoccupations; my squirrel-like mind skitters away from dire possibilities, thanks to my real world of classes to teach, manuscripts to edit, dogs to walk, dinner to make.

When my mind skitters back, those dire possibilities seem ridiculous. Like recently, when my family was due to arrive at dinnertime. I leaned into the hot oven to check a heavy Dutch oven, but could barely get the weighted rack

to slide.

I remembered my doctors' admonitions against straining and laughed, thinking, *Gee, I hope I don't keel face first onto these broiling racks. My kids would walk in and tell each other, "That's weird, smells like Mom is grilling meat." Then they'd all become trauma-induced vegans.*

I am grateful for this very human trait of adaptation. I am careful in my everyday activities, but worry has receded well into the background, behind my frustration with politics (to which I have *not* adapted) and my joy in the daily pleasures of sunrises, fresh coffee, good books and wonderful people.

I still take my phone to the barn, the better to photograph the beauty I find along the way.