

Stuck Between Floors

Katherine White

Oh, hell, no. I glowered at the print-out of my husband's lab work. *Not again.* His liver enzymes were elevated; and, this time, they were higher than they had been forty years ago, when we were newly married.

Within a year of our wedding in 1980, Glen developed a bad case of hives, including on the palms of his hands, an unusual location. The workup was extensive, the results inconclusive. As a physician specializing in neonatal intensive care, I knew just enough about adult medicine to realize that there wasn't anything straightforward about my non-physician husband's case. One of his blood tests for lupus, the ANA titer, was positive; but that diagnosis, fortunately, didn't pan out. Biopsies of the red blotches on his legs revealed a nonspecific vasculitis, which was not diagnostic of anything in particular and thus not very helpful. "My doctor says I could be, not just a footnote, but a whole chapter in a medical textbook," he said wryly. Perhaps he was always destined for unusual medical issues: when he was six weeks old and unable to keep his formula down, he required surgery for pyloric stenosis—not a rare condition, but not common, either.

Glen's immunologist contemplated a trial of prednisone for the hives, but first she wanted to screen him for any occult viral infection that could worsen on the powerful corticosteroid. Bingo: his hepatitis B surface antigen was positive, and his liver enzymes were mildly increased, consistent with a smoldering hepatitis B infection. Whether or not that had anything to do with the hives or the other abnormal tests was an open question, but one thing was certain: no prednisone for him. Also, no alcohol—not until those enzymes came down. This was a blow to both of us; we were sociable thirtysomethings who enjoyed drinking with friends at parties and informal get-togethers, and we liked to kick back with a cold beer at the end of a hot summer day.

The mild enzyme elevations persisted throughout the '80s, while our family expanded to include three daughters, and well into the '90s, as the girls grew from infancy to adolescence. Between working at our challenging jobs and attending our kids' soccer practices and games, school plays, and band concerts, our lives were filled with the joys and anxieties of parenting and with the mutual support and negotiation of marriage. We seldom acknowledged the nagging drone of worry that hummed beneath our days. With one or two exceptions, Glen managed complete avoidance of alcohol the whole time. "Do I want a drink, or do I want to see my kids grow up?" he'd say, with a philosophical shrug. At some point around the halfway mark of our now four decades together, the liver enzymes normalized, and Glen was able to enjoy his pint of Guinness or glass of single-malt scotch once more. The axe hanging over our heads had been lifted, for now.

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One evening in late June of 2009, Glen cleared his throat as he leaned against the kitchen stove, ankles crossed. “You know that nevus on my retina they’ve been watching?”

“Ye-e-e-s...” My eyebrows shot up. His ophthalmologist had been following a mole on his retina for the last few years—yet another medical oddity to add to the textbook chapter. I’d looked at the brightly colored pictures in his medical chart each time he had a scan, and they always made me uneasy. I had a feeling I knew where this was going, and it wasn’t anywhere good.

“Well, it’s turned into a melanoma.”

My heart pounded and my breath caught as I crossed the kitchen to hug him; we clung to each other for a few minutes. When we pulled apart, I said, “What, you couldn’t have had something normal people get, like a cataract?” He chuckled, and we reverted to our usual coping strategy, making light of whatever is serious and speaking of it, when we did so, in casual or ironic terms.

The incidence of retinal melanoma is somewhere around 5 or 6 per million people, but the potential for a deadly outcome is significantly greater than that of an indolent hepatitis B infection. I tried to hold on to the good news—the thickness of the retinal tumor was such that it was likely to respond well to treatment, and my husband would not have to lose his eye. But looking at the situation from a physician’s point of view proved problematic for me: as a neonatologist, I’d always had to be ready for the worst—not just prepared for a “bad” delivery, but perpetually aware that even a growing preemie or a stable term newborn could develop life-threatening illness in a matter of hours. Even so, putting on my doctor hat offered a little bit of welcome objectivity.

But this was my husband. We’d had three decades together; how much more time would we get?

Glen’s ophthalmologist arranged for him to be treated at the Wills Eye Hospital in Philadelphia. Three weeks—and one niece’s wedding—later, we drove to the City of Brotherly Love. We both had a little familiarity with the place from earlier chapters of our lives, but not enough to really know our way around, so it took us a while to locate our hotel, a narrow brick building not much bigger than a row house but as close as we could get to Wills—only seven blocks—where we planned to hoof it at the crack of midsummer dawn the next day.

My husband remained preternaturally calm while we checked in, as is his custom; but I was a hot mess. When I packed for the trip, I’d included a small fabric bag of jewelry to act as a talisman: the thick gold ring my late mother always wore on her right hand, her grandmother’s wedding band; my recently-deceased father’s wedding ring, delicately engraved on the inside; a gold charm in the shape of a *hanzi* on a necklace my mother-in-law gave me after their trip to China; the signet ring Glen put on my finger the day we got engaged, a placeholder for the diamond we purchased later; and other jewelry he’d given me in the years since—on our wedding day, at the births of our daughters. I hoped these material tokens of love would protect us from the worst of the things that could go wrong.

My talisman was not proof against lesser calamities, however: when we took the tiny elevator to the sixth floor, it got stuck. Between floors. I'm claustrophobic at the best of times, so my anxiety skyrocketed into stroke territory as Glen pushed the alarm bell and we waited for help. Even my unflappable husband looked anxious. *Perfect*, I thought. Here we were, not only stuck between floors in an elevator, but suspended between a serious disease and its treatment. Plus, physician or no, I was as helpless in the face of all this as my husband. Finally, the elevator was coaxed into opening partway at the second floor, like a Dutch door, and we hoisted ourselves out. I was off like a shot, running up the remaining four flights of stairs to our room.

The following day, Glen had a radioactive seed implanted behind his retina under general anesthesia. For the week the device remained in place, we stayed in a nearby nursing home where one of the upper floors was dedicated to Wills patients. The irony of being quartered in a nursing home was not lost on us—as if a cancer diagnosis weren't enough of a reminder of mortality. He was not allowed off the floor, a situation we jokingly called “house arrest.” Fortunately, I was permitted to leave the premises for long walks, which were vital to my mental health and from which I usually brought him back some kind of treat. To my relief, the elevator worked just fine.

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Glen's retinal melanoma responded well to the radiation treatment. Melanoma in this location tends to metastasize, not to the central nervous system as one might expect, but to the liver and/or lungs. A decade of biennial chest X-rays and liver MRI scans ensued, along with routine blood tests, and all seemed well. We celebrated ten years melanoma-free in 2019—though, as I've since discovered through informal consultation with Dr. Google, the likelihood of recurrence in liver or lungs doesn't become negligible until *fifteen* years post-primary tumor. In the meantime, we'd slid into our seventies, and Glen had begun to experience more mundane medical conditions like hypertension, leading to more medications including a statin. And then, those pesky elevated liver enzymes. Though the enzymes decreased perceptibly after a trial off the statin, they didn't revert to normal, and other blood tests presented a puzzling picture, so he had another MRI and a liver biopsy which revealed no evidence of melanoma or other pathology. Another reprieve.

Over the years, the axe that's been hanging over our heads since the start of our marriage morphed into a double-bladed one: liver disease on one side, melanoma on the other. Its handle remains delicately poised over our heads. But I don't feel quite like I did when we were stuck between floors in that elevator. This time, there's less panic, more resignation; we are older, after all, and the kids are grown. At our age, health problems are simply to be expected.

Plus, we've been here before. Sort of.

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