
the trike and the 49 bus

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We had it down pat. As soon as I'd hear that "Mar!" I'd yell back "Okay!" so I wouldn't have to hear it again. I'd hear it again anyway. "Mar! Toilet!" I'd sink; I'd shrug; I'd tantrum, to myself or aloud.

I'd race up the stairs and down the hall to Jeff's wheelchair, which we called "the trike." I'd unlock both brakes at the same time, spin around to the back, zoom through the two doors, enter the bathroom backwards and swing clear of the sink, then spin around in front and lock both brakes at the same time. As fast as possible, I'd undo Jeff's belt, un-Velcro his pants, pull off the side of the chair nearest the toilet (sometimes it would stick), brace his legs and then my legs (making sure he'd gotten hold of his pants), so he could push down while I pulled up. Then I'd bend down, lift his right arm around my back, make sure he could lift his left arm today. (His left arm was his good arm, then; he *had* a good arm, then.) Then I'd pull up and try to stay up so he could make sure his pants went down. Using both my knees I'd ease him down and onto the toilet, and steady him between my knees. (That was a discovery, using my knees

as though they were limbs.) I'd put the side of the chair back on so he could lean on it, and I'd put a jar on him, too, in case he'd need it for urinating ("toilet" meant defecation).

Then I'd go back to writing, typing, Scrabble with the kids, playing the piano, correcting calculus papers, or supper. I could, or at least I did, eat under those circumstances; one of the reasons I'd eat instead of wait for him was so I wouldn't be away from the supper table, and the kids, any more than I had to. "Ten minutes, okay?" I'd ask him, hoping he'd answer, "Okay," hoping he wouldn't say "I need you to balance me" or "Could you just scratch my left ear?"

In ten minutes, maybe fifteen, I'd run back up, hoping he'd say it had been a false alarm but knowing that if it had been he'd soon be calling "Mar!" again—and then there'd be two interruptions to dinner, at least. If it was a "success," as he'd call it, I'd pull him forward, leaving four inches of space between him and the inside back of the seat. I'd leave that space—that "steamy triangle," I called it in the title poem from *Epsilon Country*—for the paper to fall into, hoping it would fall and not get wedged in there.

Sometimes I'd pause at this point to look through the slightly open bathroom doorway at sleeping Devin, our child of those years, still a baby; I'd sneak a look at those almost blond curls and those Bubbalah hands lying gracefully in the most ungraceful positions; I'd sneak a peak or two at the happiness that got us through those years. Anyway, then I'd wipe, starting far enough down so I'd get it all, which would mean fewer wipes, and I'd pause again, pause and think back thirty years, to imagine my mother saying not "Have you and Jeff been petting?" but "Have you and

Jeff been wiping?" If she didn't approve of him then—I'd almost laugh when I thought of this—what would she think of him now?

To get him up again and the pants back on, we had a new trick (we were always having new tricks). I'd pull Jeff forward and all the way to the left so I could pull up his pants on the right side. Then I'd shift him all the way to the right so I could pull up the left side. Then I'd get in back and sort of juggle him a little, which would eventually bring up the middle of his pants. I'd buckle, then Velcro, then lift up his left arm and put it around me, then the right arm. I'd brace all four of our legs and lift, lift, lift him back into the trike. It was higher than the toilet seat so I'd have to grab onto the grab bar with half a hand. I'd run him back to the bedroom, and remember to put him close enough to the phone, that lifeline. Otherwise I'd be hearing that "Mar!" as soon as I was settled back at dinner. I'd set the little table in front of him and there we'd be, right back where we'd started minus what I'd just flushed or wiped.

That was in the days when he could call "Mar!" loud enough for me to hear him from downstairs, when there didn't have to be someone upstairs with him at all times, when he could still answer the phone if not dial, and when he still lived at home. It was, even then, the speaker phone, the same one he uses now at Inglis House, the nursing home, although today someone has to be in his room in order for him to answer and still his voice comes through pretty weak. That was in the days when he could sit up in the trike all day, when he had the energy, if not the ability, to shift at least slightly so his behind wouldn't hurt.

It feels strange to think back to that time. It feels stranger to think back even further, to when our lives were “normal,” “regular,” and multiple sclerosis was a vague distant term; perhaps we’d heard of the MS Society, perhaps not. ■

Jeff and I met on a bus in 1958; I was fifteen, he seventeen. Jeff was on his way home from what was then Newark College of Engineering; I was returning from my day at Arts High, a music and art high school in Newark, New Jersey, to which I commuted from small-town Roselle, because I played the piano and because I’d been miserable at Roselle High. Jeff picked me out, he likes to remember, because I “looked cute”; he put his books down on the seat next to him so no one else could sit there, then he removed the books for me. We wound up talking about our common interest in math, in particular about the book *Flatland*, George Abbott’s nineteenth-century fantasy about worlds of both less and more than three dimensions. (The person who wrote the introduction to that book, and who is to be credited for bringing it back into circulation, would later be a physics colleague of Jeff’s.)

It took Jeff and me a year and a half to start dating, but we kept meeting on that number 49 bus and talking about math. It was never acknowledged but always in the air that we meant something to each other, that eventually we would wind up together.

Our relationship was one of both minds and bodies. We talked about everything; there were no secrets (at least no conscious secrets). Since the day we finally said that we loved each other and would be joining our lives, I have