

OUTROLL, OUTMANEUVER, OUTLAST

“Sorry, pookie, I wet the bed.”

Gary’s voice rips me from sleep. Nauseous and disoriented, I grope for the walkie-talkie on the night table and press the talk button. “Can a person die from being woken up at the wrong part of the sleep cycle?”

Gary’s laugh crackles through the walkie-talkie. He doesn’t realize that, at the moment, I hope the answer is yes – or that someone would go ahead and shoot me. I’ve heard it said that a person’s capacity to handle stress can be likened to a rain barrel. Well, Gary’s been peeing into my barrel all day, and I’ve reached overflow.

I haul my fifty-year-old body out of bed. In the dark, I slide my hand along the walls and stumble out of the unfamiliar bedroom and into the unfamiliar living room, to the hospital bed placed in the apartment by the Outpatient Day Program staff. A table lamp is on, and Gary, his arms no longer bone-thin but not yet of his normal musculature, is pulling on the far bed rail to haul himself upright. Naked except for a yellow t-shirt reading “Outroll, Outmaneuver, Outlast,” he pushes down on the bed with his hands and hops his forevermore numb butt sideways to a dry spot. A urine-blot is revealed. A big sopping Rorschach test. What do I see in it? Myself, drowning in urine. Gary was supposed to thread a catheter into his penis at midnight, only minutes away, but his bladder wasn’t able to wait. Again.

I trudge to the bathroom to get Gary a wet washcloth and a towel so he can clean himself.

“Maybe you’ve got an infection,” I say.

“We’ll call the hospital in the morning.”

“I’d like to throw you right back into the hospital.”

Gary laughs, and because he thinks that’s funny, because it’ll only add more drops to both our barrels if I stay a crab-ass, I chuckle, though I sorely wish tossing him back into the hospital was possible. This day, the day of his discharge, fifteen weeks after his car accident, started off on the wrong foot—I suppose that should be “wheel”—and we’ve been spinning in circles ever since.

Shortly before nine a.m., I’d walked into Gary’s room at the spinal cord injury rehab hospital, only to find him on his back in bed instead of his usual up-and-at-em.

“When Karen¹ turned me this morning,” he says, “she found a red spot on my thigh. She thought it might be a first-stage pressure ulcer.”

I drop my rolling portfolio and rush over, get my nose down and peer at a three-inch-diameter pale pink area. “It’s a lump.”

“Yeah, now Karen thinks it’s a bug bite. She put in a call to Dr. Shen.”

I bat Gary’s shoulder. “Cripes, give me a heart attack, why don’t you?”

At the hospital Gary was first helicoptered to, the nurses were remiss in turning him. I didn’t even know Gary should be turned. By the time I was told he had an ulcer on his sacrum—God knows how long after he got it—it was so severe that this second hospital performed surgery. Now we have to pay for it, and I’m not talking the \$130,000 bill or the extra hospitalization. I’m talking the yearlong post-surgery restrictions. They impede Gary’s progress toward developing the skills for independent living, while I’m the one who shoulders the extra labor—and these shoulders ain’t what they used to be.

¹ The names of the hospital personnel have been changed

I prod the smooth pink spot. “I dunno, Gary. My guess is, you tore a muscle.” I don’t ask Gary to speculate how that could’ve happened, he being unable to move or feel anything below nipple level.

Dr. Shen wheels in, his injury one level worse than Gary’s. He feels the lump, says to put ice on it and stay put, spins a one-hundred-and-eighty-degree wheelie, and races away. I can’t move fast enough to throw myself in front of his chair and ask him what the deal is.

No point packing up until we know Gary will be discharged, so I take my laptop from my rolling portfolio and set it on Gary’s bedside table. I blog the previous day’s activities: Gary and I together got officially checked off to do transfers between wheelchair and car. Gary didn’t get checked off to do any kind of transfer entirely on his own. Gary went on a baseball outing with fellow patients and embarked on a solo, perilous journey through the crowds to the concession stand and returned triumphant with a hotdog.

“Won’t be long now until you can continue writing your novel,” Gary calls to me, lying in bed viewing his laptop.

Hard to imagine taking up fiction again. When I got the call about Gary’s accident and was running around throwing things in the car for an extended stay away from home, I threw in a boxful of notes for my novel. I’ve never looked at them. Writing a mystery, once my greatest passion, seemed a trifling pursuit, selfish, with Gary lying with his spine cut in half.

“I’m glad you’ve been able to continue some sort of writing during this time,” Gary adds.

Those first days, my biggest fear was that Gary could still die. My second biggest fear—well, other than the stress causing me to relapse into illness—was that the accident would break his spirit. Perhaps I was projecting. Fourteen years ago, I came down with severe Chronic Fatigue Syndrome. The first, worst, years, I’d essentially been bedridden, life passing me by. I

didn't want Gary to experience such loneliness. So, I emailed: family, close friends, math department colleagues, then, hell, I hijacked the entire email list of the annual math conference Gary attends—and I used to attend before my illness forced me to take disability retirement. I began the blog as an efficient way to respond to everyone's emails and to apprise them of Gary's condition.

I soon discovered I feed on blogging. It gets me out of my head, keeps my courage up. Because my audience includes my and Gary's mothers and siblings, the blog disciplines me to seek out silver linings, and to polish tarnish with humor.

Not that I ignore the clouds. To keep those cards and letters coming—ostensibly for Gary—I open up on the blog. I shared my blackest moment: three days after the accident, Easter, a day whose message of hope I found meaningless, cruel. I took my readers on the emotional roller coaster of Gary's medical progress and setbacks of the first month. And since rehab began, they've seen us lay, brick by brick, the foundation for our new lives—resurrection, after all.

“Hey, look at this, pookie, we're famous,” Gary calls. He nods at his laptop.

We're front page news on the electronic version of our hometown paper.

“How do you like the last quote of mine?” Gary says.

I read: “‘I was never depressed,’ Professor Gruenhage said, attributing much of that to his wife. ‘It's much, much harder to go through this alone.’”

I blot my eyes on my sleeve. “I like it very much, pookie. But I'm not sure it's true. I don't think you're the type to get depressed.”

“It *is* true, I *would* be depressed.” Gary reaches out an arm, and we hug, both with the waterworks going.

A couple weeks back, the assistant chaplain told me it says a lot I'm here with Gary, that

many people can't handle dealing with their family member who's suffered this kind of accident. The chaplain's words reminded me of when I'd joined an internet Chronic Fatigue Syndrome support group and found out that spouses were leaving their ill partners right and left. Gary stuck by me, with no guarantee I'd recover; it was years before things stopped getting worse and more years before things started to turn around.

Gary gives me another squeeze. "I especially love your last quote," he says.

I read: "I have always thought of him as the most wonderful person in the world, so it's not like I feel burdened helping him."

My guts roil. Certainly, the "most wonderful" part is true. And, I've enjoyed rehab, learning right along with Gary, helping him develop his skills—and turning into a harder taskmaster than anyone on staff, Gary jokes. He's imitated me talking to the therapists and nurses. "Are you sure he doesn't need more weight on the rickshaw machine?" "Yes, he can do another hour of therapy without a break."

So "not feeling burdened" *has* been true. Which I'm thankful for, since then I didn't have to lie to the Mikette Wallace interviewer—I couldn't believe the wet-behind-the ears twerp asked me if I found dealing with my husband a burden.

But the test is to come. I thought Gary would be much further along at discharge.

"You *are* the most wonderful person in the world," I say.

"No, you are," he says.

"Okay, I am," I say, knowing he will laugh.

A couple hours later, Gary's doctor agrees with my diagnosis of a torn muscle and says to ignore it and that Gary is good to go. I wish he would've told us that earlier. For the next two weeks Gary and I are participating in the hospital's Day Program, which we hope will ease our

transition to operating independently of hospital care; I'd wanted to get settled into the Day Program apartment as soon as possible. I console myself with the reminder that the time didn't go totally down the tubes: I used every minute to craft my blog post. I've uploaded all the pictures from yesterday's graduation ceremony, where I cried as Gary wheeled in to "Chariots of Fire." From the Skin Care Team, Gary received a "Shiny Hiny" award—a certificate in the shape of a butt and covered with aluminum foil; I feel this award is partly mine, since early on in the post-op stage I took over dressing his wound and was always fussing at his nurses over whether they'd positioned him far enough over on his side. From the OT's and PT's he got a "Most Likely To Need A Helmet While Doing Wheelies" certificate, this for falling over backwards while practicing unsupervised and smacking his head on the floor and nearly causing me to have a heart attack.

I roll Gary's wheelchair to the bed, angle it, and lock the wheel locks. Gary hops his butt to the edge of the bed and uses his hands to lower his legs over the side and position his feet: left one on the chair's foot plate, right one on the floor. I stand behind Gary and wedge my hands under his sit bones. Thank goodness Gary has progressed to the point where I'm not providing the majority of the lift. Gary is down to one-twenty-six from a pre-accident one-forty-five, but I weigh only a hundred. Not to mention my bad back and my Chronic Fatigue Syndrome, which, while having moderated, is still hovering over my head.

One hand on the bed, the other on the wheelchair, Gary uses his arms to swing his upper body from side to side in the way he's been taught and, on the count of three, he pushes off the bed with his hand. With my support, he makes a controlled landing onto the chair.

Karen, Gary's head nurse, totters in with a mountain of empty boxes. I begin packing Gary's belongings. Hanes men's lounge pants, easier for us to get Gary into; T-shirts and

sweatshirts, easier than button-downs; DVDs and tapes and players and books, all having gathered dust since rehab began ten weeks ago—though they saw plenty of use the month prior, when Gary was flat on his back hooked to a ventilator; a drawer chock-full of chocolate bars, I having mentioned on my blog that Gary is a chocoholic.

And I pack Gary's medical supplies. Tons and tons of medical supplies. Bowel program, bladder program, skin care program, reacher tools, etcetera. No more will Gary simply sit on a toilet and do his thing, no more will he naturally wiggle around to relieve the pressure on various parts of his skin, no more will he stand and grab for something he wants.

I glance at him, then stare. "Your crotch is wet."

Gary looks down at himself. "I can't believe this."

Gary is peeing into his wheelchair, his first ever bladder accident. I cover his bed with towels, and we transfer him back into it. Because of his sacral surgery, he isn't allowed to have his legs bent past a certain angle, so instead of his going through the rigamarole of pulling and sliding one leg, then the other, onto the bed, I have to—careful of my back—pick up his legs for him and then help him get his pants off. He lies on his right side and I lower the pants on the left side a few inches until they won't go any farther. He swings his arms up and over a few times until he's built the momentum to flop onto his back. Then, instead of doing a similar arm routine, he reaches around and grabs my butt to help roll himself onto his left side.

"That's an illegal move," I say.

He waggles his eyebrows. "Whatever works."

I lower the pants on the right side a few inches. He rolls, I tug, he rolls, I tug, again and again until the pants are down far enough for me to tug them off the rest of the way. I get him a washcloth and towel, and he cleans himself. Then we reverse the dressing process.

“Next time,” I say, “we’re transferring you from the other side. You obviously got up on the wrong side of the bed.”

From the bathroom adjoining Gary’s room, I collect his bladder program supplies—washcloths, towels, catheter, collection bag, KY Jelly. Despite the peeing accident, Gary starts catheterizing himself on schedule, to make sure the snake is drained. As Gary coaxes the catheter in, he pulls up on his penis, to make it easier for the catheter to reach the bladder. His penis stiffens in his hand. Nerve impulses are swimming upstream his spine, but will be unable to leap the chasm at the Thorax 4 vertebra.

Gary glances at me and, evidently having read something in my face, says, “I’m sorry for the younger guys.” He returns his attention to his task.

“Sorrier than for you?”

He smiles and shrugs. “Been there, done that.”

Yeah, well, I been there, done that, am going to miss not doing it with him “the usual way” ever again. Oh, there are drugs he could take, or some kind of pump that could be used. But I’m not a fan of drugs, and I wouldn’t want him to take them on my account. And I can’t see pumping him up for me to sink down onto. Too much work on my part, when all his desire and excitement is going to remain in his brain, like having a craving for chocolate while no longer having taste buds

The four-inch-high, two-inch across, interconnected rubber air cells of his seat cushion—seventy-two of them, at the moment reminding me of a forest of squat black penises, and I really need to get my mind on other things—may be great for “creating a counter-pressure environment for the prevention of ulcers over the sit bones,” but they’re a pain in the butt to wash and dry. I set the cushion on the floor of the roll-in shower and rinse off the urine with a shower hose, then

with a towel I dry each squishy little penis. Um, “fat finger.” I push and yank the cushion into a seemingly too small spare seat cover.

I angle Gary’s chair so he can transfer. Gary starts placing his feet with his hands. For some reason, he can’t get his left foot how he wants it. Ready to get a move on, I want to grab that foot and plunk it into position. But I don’t. “Tough love,” the staff here calls it. Don’t do for your loved one what he should be learning to do for himself. Even those times it aggravates the hell out of you.

Gary laughs. “I can’t believe how long this is taking me.”

He amazes me. I’d be cursing, slamming my useless foot around—

God, I’d break if he had my disposition instead of his.

I flash back three weeks to one of our patient outings—Dick’s Sporting Store. Gary is in a dressing room trying to get a pullover shirt on. He flails around, grabbing at some part of the shirt for a quick yank, then grabbing at his wheelchair to regain his balance. The shirt gets stuck over his head. I’m standing there feeling sorry for him, thinking how long it’s going to take him to dress himself—so far, the nurses have been dressing him—when a guffaw bursts out from under that shirt. My husband, laughing his head off—and to look at him, you’d think he’d literally done that—with his shirt stuck up under his armpits. We both laugh so long and hard I fear the salesclerks might come and throw a net over us.

Thinking of that now, I chuckle. Gary looks up at me, finally finished fooling with his foot. “Sometimes,” he says, “you just gotta laugh.”

I pray I’ll always be able to stop and laugh with him.

We get him transferred, and I resume packing. Gary stuffs into plastic bags his multitude of pillows—used to pad him off in bed to prevent skin ulcers—but other than that, in this small

space between closet and drawers and hospital bed, he's a hindrance, not a help.

My blinkers—the ones I put on two-and-a-half months ago to get me from day to day—again slip. Is he still going to be able to do the dishes? Lift the lid of the three-and-a-half-foot-high city garbage can and toss our garbage in? I equate household tasks with women's bondage—a little extreme, perhaps, but there you are—and once my fears about the dangers to his life and psyche passed, my fear has been that I'm going to be stuck with more than my share of the drudge work.

At 2:30, I have everything packed, all forms have been signed, all goodbyes said. We birdies are being pushed from the nest. I roll one hospital cart loaded up with boxes, Nurse Karen rolls another, and Gary rolls himself. I help Gary transfer into the car by aid of a 8x24 maple board. I nudge one end under his butt and put the other end on the car seat. Gary hops along it, while I keep my hands on his waist to make sure he doesn't fall off backwards or forwards.

Karen and I get everything shoved into the Escort, including Gary's de-wheeled and top-folded-down wheelchair.

"Don't forget to take care of yourself," Karen says to me. "Remember the 'Emotional Adjustment' lecture."

I goose her with Gary's two-foot-long reacher tool. "That lecture came months too late."

The lecturer said we caregivers need to talk straightforwardly with our loved one about how we're doing. But I can't tell Gary how tired I am sometimes, or how much pain I'm having. He has enough to cope with.

I drive down the hospital driveway, giving Gary his first car ride since his accident—not counting ambulance rides. Though Gary has his seat belt on, he's wobbling around like a bobble-head doll. When I brake for the red light at the end of the driveway, he sails for the windshield. I

whip out an arm to stop him, and he grabs the dash.

“For gosh sakes,” I say, “we’re going to have to rubber cement you in.” He laughs.

Fortunately, we’re only going across the street. After I park, I wrestle the fifty-pound chair out of the car and pop on the big wheels. I let Gary into our apartment, then carry in the boxes. When I finish, my gaze is drawn to Gary.

He’s staring at his crotch. He slaps himself on the forehead. “I’m like a baby.”

Worse. A 126-pound baby. I never even wanted one of those dinky ones. “Good thing you’re a cute baby.”

Tug, roll, tug, roll, and tug, roll some more, we get his pants off. He cleans himself, I wash and dry the mocking forest of penises, and tug, roll, tug, roll, we get Gary into another pair of lounge pants. I unpack boxes, help Gary organize his things, and see to the urine-soaked laundry. We eat takeout pizza.

Somehow, it’s already 7:30, time for Gary’s evening routine, and I’m plodding like a mule going around and around turning a grinding stone. We transfer him into bed, and I hold his millstone legs in various stretches. Next, we tug-roll him out of his shirt, out of his pants. I wash his legs and back, he washes the rest of him. I help him into a prone position so I can change his butt bandage, since the large triangular surgical “flap” over his sacrum still isn’t healed.

My eyes trace his other surgical scar, running along his spine from mid-back to neck. Titanium rods were inserted, so he won’t sit collapsed forward like a rag doll. Zillions of staple marks pock the skin to either side of his spine. When I saw the bill from the first hospital for half a mil, I told Gary that we could’ve saved a heckuva lot of money by buying the stapler at Wal-Mart and me stapling him back together.

I kiss the nape of his neck. He turtles his neck into his shoulders. “Mmm,” he says.

“What’s that for?”

“Cuz I loves ya, pookie.”

The routine takes an hour and a half, and the night isn’t over. I go to the grocery: milk and cereal for breakfast, and, since Gary and I both need cheering up, flowers. I get back at ten. Gary is asleep. So much for the flowers.

Instead, I cheer myself up by writing a blog post, then go to bed. I know Gary has to do another catheterization at midnight, know that afterwards he’ll need help getting prone. So I’m expecting his walkie-talkie call. But I don’t expect it to come seemingly seconds after my head hits the pillow and that it’ll involve another peeing accident.

Yes, I sincerely wish we could check him back into the hospital. And while I’m wishing, I might as well wish we could go back to April and this time have Gary see the oncoming car and not turn into its path. But now, I have to get him out of his wet bed.

I re-do the bed, get Gary back into it, put in the nth load of laundry. After Gary finishes catheterizing, I help him get prone. Since he’ll stay in this position for the next six hours, he needs to be padded off with care. I place pillows so they’ll end up under Gary’s chest and above and below his knees. I bend his left leg up at the knee, lay that leg over his right leg, and then give his hip a little push on the count of three as he swings his arms to give himself momentum to flop over.

“Remember how they said we’d have to find a new normal?” Gary says as I put a sheet and two blankets over him.

“Yeah,” I say. *Life is the same*, the rehab program alum leading one of Gary’s classes had said. *But the approach is different*.

“This better not be it,” Gary says.

He can damn well say that again.

I hand him a pillow, and he scooches it under his face to lie on. I kiss his cheek. As I start for the bedroom, I hear, “Pookie . . . ?” By Gary’s soft rising tone, I know he’s going to make a request I’m not going to like.

“I need to figure out how to get out of the prone and onto my side,” Gary says.

“Uh, what do you mean, ‘figure out’?”

“I haven’t tried that with covers on. Maybe I should practice now, so I don’t have to wake you at six.”

“Oh, God, Gary.” I restrain the stronger curses that spring to my lips. He was supposed to have practiced that with his nurses.

Gary grasps the pillow under his face, his knuckles white. “I thought the things I was still letting the nurses do for me would be easy. But they’re not.”

All along, I’d figured things were going to be harder than he’d thought. But everything’s turning out to be even more work than I’d expected. I’m afraid. Afraid I’m going to break down ill, or be swallowed up in his new normal.

Turn off thoughts. Turn off feelings. Just get from this moment to the next, a mental putting of one foot in front of the other, like a person lost in a snowstorm hoping sheer movement will lead out of the worst of it.

I stand watching awhile, but Gary can’t get onto his side, both the pillows and the bedclothes insurmountable obstacles. I’m not only going to have to interrupt my sleep every night midnight, but every morning six a.m. Goddamn.

I have an idea. Feeling small, I say, “Try using your reacher.”

I pick it up from his bed table and hand it over. If he tells me this is just too much for

tonight, that he'll practice getting out of the prone tomorrow during the day, I think I'll have to cave. I want to cave anyway. I want to go to bed.

Gary doesn't say anything. For ten endless minutes, he plucks and stabs at bedding and pillows, gets all wound up in the covers trying to arm-crawl his body into different positions, and struggles to shove his legs around with his hands. And this is the way it's always going to be. He's not going to get over this.

Finally Gary is out of the prone and lying on his side. I help him get back into the prone. He settles onto his stomach, his face stiff, his eyes hollow. I have never in my twenty-eight years with him seen him this way.

I want to run out of the apartment, and scream, and beat my fists on something, on that something that thinks it's fair to do this to this lovely man.

"Are you okay?" I say.

"Yeah."

I don't even recognize the quiet, clipped, flat voice coming out of him. "Are you a little frustrated?"

"It's hard," Gary says, his voice breaking.

I start crying. I move behind the bed so Gary won't see. I pet Gary's head. "I know," I say. And I can't stand there any longer.

I turn off the light and hurry away, away, away into the bedroom.

Flying past the chest of drawers, I knock a packet my mom sent. Now strewn across the floor are a fistful of old wedding photos, sent in celebration of my and Gary's 25th wedding anniversary, coming up in two days. I turn on the light and pick them up. I pause on one. I'm standing in mom and dad's backyard, wedding guests seated at patio tables in soft focus behind

me. My long slim white cotton dress has a ruffle at the bottom and thin red ribbons for shoulder straps and belt. Bought by mom at a boutique, the dress was labeled a nightdress. It's simple and pretty and definitely not too wedding-y for our put-together-ourselves wedding.

Gary, with longish hair and actually wearing a tie, is feeding me a too large piece of mom's red velvet cake. Appropriate, since at the time I was wondering if I was biting off more than I could chew. I had never in my life intended to get married. I hadn't wanted the societal benediction "the two become one—him."

But I'd wanted to spend my life with Gary. He was intelligent, kind, sweet, patient, generous, had a great sense of humor—and was cute, to boot. Most importantly, after living with me for three years, he knew me fully and—surprise!—apparently still found me desirable.

My ambitions are this and this and this, I'd told him. My interests are this and this and this. I will not give them up.

I envy your passion, Gary had said.

I will not do that and that and that. That's the way I am. I am not an easy person to live with.

You are intense, Gary had said. You are feisty. That is you. I love you.

And what if in the future, I develop new ambitions, new interests, new things I won't do?

I want you to do what makes you happy, Gary had said. And I want us to be together, always.

In the end, my list of pros and cons hadn't decided me. My fears hadn't stopped me. I took the leap, simply because I also wanted us to be together, always. I could not give up being loved.

I hear noises from out in the living room. Small hitching noises are coming from Gary's

throat. I go to him and stroke the back of his t-shirt. Outroll, Outmaneuver, Outlast. Especially, Outlast.

“Aw, Gary,” I say.

“I’m mostly okay with this,” he chokes out. “But I hate seeing you running yourself ragged on account of me.”

I squoosh into the hospital bed with him. I want to wrap myself around him, crawl right inside him.

“Things will get better, I promise, pookie,” he says.

“I know they will. Anything Dr. Shen can do, you can do better. And, by the way, yes, I’ll marry you.”

“Huh?”

I switch on his bed table lamp, give him a big fat grin, and show him the wedding photo of me slipping a ring onto his finger and promising in sickness and health. “I never actually said yes when you asked if I wanted to get married. I just never said no.”