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COPING *with* THE NEW NORMAL

BY PEG DANIELS



“SORRY, POOKIE, I WET THE BED.”

Gary’s voice rips me from sleep. Disoriented, nauseous, 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 puts me out of my misery. 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 50-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, injured at T4, 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 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 cath himself 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, I chuckle, though I sorely wish tossing him back into the hospital was possible. This day, the day of his discharge from rehab, 15 weeks after his car

accident, started off badly. Shortly before 9 a.m., I’d walked into Gary’s room at Shepherd Center, only to find him on his back in bed instead of his usual up-and-at’em. They had found a first-stage pressure sore, another one, this time on his thigh.

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, it was so severe that surgery was necessary. 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 becoming independent, while I’m the one who shoulders the extra labor—and these shoulders ain’t what they used to be.

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 e-mailed. Family, close friends, Gary's math department colleagues, then, what the hell, I hijacked the entire e-mail list of the annual math conference he attends (and I used to attend before my illness forced me to take disability retirement). I soon discovered I feed on blogging. It disciplines me to seek out silver linings, and to polish tarnish with humor.

Not that I ignore the clouds. I open up on the blog. I even 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.

Earlier in the day, at the hospital, Gary discovered on his laptop that we were front page news on the electronic version of our hometown paper.

"How do you like the last quote of mine?" he 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 after 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 imitated me talk-



*Not feeling
burdened' is true.
But the test is
yet to come.*

ing 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." "I think he should be practicing his bowel management program every day now."

So, "not feeling burdened" has been true. But the test is yet 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.

"OK, I am."

A couple hours later, the doctor's assistant tells us the red spot on his thigh is a torn muscle and to ignore it. Gary is good to go. 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.

LEAVING REHAB BEHIND

As the moment of discharge nears, Tami, Gary's head nurse, totters in with a mountain of empty boxes. I must begin packing Gary's belongings, including medical supplies. Tons and tons of medical supplies. Bowel program, bladder program, skin care program, reacher tools, etc. I glance at him, then stare. "Your crotch is wet."

Gary looks down at himself. "I can't believe this." He is peeing into his wheelchair, his first ever bladder accident. I cover his bed with towels, and we transfer him back into it. I 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 him onto his left side.

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

He waggles his eyebrows. "Whatever works."

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 fourth thoracic 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. Will it be forever? 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 rubber air cells of his ROHO cushion — 72 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 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. I push and yank the cushion into a seemingly too small spare seat cover.

I angle his wheelchair in so Gary can transfer. He 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.

We get him transferred, and I resume packing. Gary stuffs into plastic bags his multitude of pillows we use 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 blinders — 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 3.5-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 Tami rolls another, and Gary rolls himself. I help Gary transfer into the car by aid of a 8-by-24 inch maple board, and Tami 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,” Tami 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.”

TESTING THE NEW NORMAL

We’re finally “home,” situated in our temporary apartment. 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”

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over his sacrum still isn't healed.

My eyes trace his other surgical scar, running along his spine from mid-back to neck. 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 10. 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, and 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 will 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.

"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.

"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 more vehement 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.

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I stand watching a while, but Gary can't get onto his side, both the pillows and the bedclothes insurmountable obstacles. I have an idea. Feeling small, I say, "Try using your reacher."

I pick it up from his bed table and hand it over — that, at least, I will do for him. 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 10 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.

Gary is finally out of the prone and lying on his side. I help him get back into the prone. He settles onto his stom-

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

ach, his face stiff, his eyes hollow. I have never in my 28 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 OK?" 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 off a packet my mom sent.

Now strewn across the bedroom floor are a fistful of old wedding photos, sent in celebration of our 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 hadn't wanted to get married, 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

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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, 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 OK 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. I know. 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." **MM**

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