

Virtual Mentor

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PERSONAL NARRATIVE

Through the Caregiver's Eyes: Darkness

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"I hope they don't admit me. I hate this ... hospital."

"I hope they do. I can't blame you for hating the hospital but you've been ... dying in your ... apartment."

We were waiting in the Emergency Room for the doctor to come back. It wasn't easy for Bob to go back to the hospital. He kept putting it off hoping he'd feel better the next day or so or in a couple days. Maybe the fever would go down and the shaking stop; maybe the diarrhea would slow down; maybe the breathing would get easier.

"For the first time I feel like one doctor knows everything you're going through." I had done my best to tell the ER doctor everything. "Now, maybe, they'll be able to do something." It sounded like a no-brainer at the time.

It was New Year's Eve. It had been a tough year. In the spring, they had discovered a fistula, a connection between his colon and bladder. Fecal matter was entering the bladder and mixing with his urine. He had diarrhea and ran a fever.

The doctor finally walked in and told him, "We're going to admit you for a couple days until we can get you to feeling better." I wanted to get out of there before anybody changed their mind.

Five months later, Bob receives his oxygen from a ventilator, his nourishment from a bag of white liquid that drips into his chest just below his shoulder. He has a tube through the side of his neck, in his nose and mouth. Other tubes hang down beneath the sheets that drain body fluids and there is a bag on his stomach for solids. He cannot swallow, cough, or talk. He has a new lung infection—pneumonia, maybe. He thinks he may or may not need more surgery again when he is stronger. Sometimes he says they tell him he does; sometimes he says they tell him he doesn't. I don't think he knows. I don't think it matters.

This isn't the way he wanted it last summer. He had completed his "Living Will" and "Power of Attorney for Health Care" and intended to sign a "Do-Not-Resuscitate" order before the first surgery. He had black trash bags and masking tape sitting on his dining table at home. Although I didn't like his choice of exit

plan, we both agreed that plastic bags were preferable to tubes and machines. He asked, "Would you rather have white bags with happy faces on them?"

I would have. I'm the designated body discoverer.

There was no joking about the desire to die before becoming dependent, incompetent, incontinent, bankrupt—before being hooked up to machines.

In July he had the first surgery to remove part of his colon and the fistula which attached it to his bladder, a temporary colostomy to give time for the colon and bladder to heal. It appeared successful. He had an epidural and morphine on demand. He felt little pain. He looked forward to the second surgery to reverse the colostomy.

The second surgery was everything the first wasn't. New fistulas were discovered. More of the colon had to be removed before the colostomy was reversed. There was no epidural and recovery (such as it was to be) was painful. The doctors hadn't prepared him for this and he was angry. He quit trusting them. He stopped paying attention to what they said and he answered their repetitive questions angrily telling them they didn't have to talk so loud; he wasn't deaf. Not all of it was Bob's fault; different doctors voiced different opinions daily.

He had to return to Intensive Care several times. He told me he had to go back the first time because a new nurse had pulled out a drainage tube by mistake. Staff said it was because of a heart attack. He was angry when he denied having a heart attack so I left it as a tube story. The tube story eventually became that he might have pulled it out himself; he couldn't remember.

I began to suspect that I couldn't depend on what he remembered. I might know more about what was going on with him than he did because I wasn't sharing the morphine.

They sent him home to get built up for more surgery but his condition deteriorated. There were still more fistulas. He experienced diarrhea every 10 or 15 minutes 24 hours a day 7 days a week. He ran a fever, chilled and shook. Antibiotics didn't seem to work. He had trouble breathing. He was losing strength, wasting away. He wasn't well enough to make a lot of his follow-up doctors' appointments.

He was hanging on to the counter waiting to sign in for a urologist's appointment. I told him to go sit down and I would sign in for him. When I got back to him he told me, "If I didn't know better, I'd swear I was having a heart attack"

"When did it start?"

"In the shower this morning."

"Shall I tell them at the counter?"

"No, they'll be calling me soon."

Then he gave me a piece of paper with some phone numbers on it. "I think they'll be keeping me. Call these people for me."

"When did you write this?"

"After my shower. Maybe you should tell the lady at the counter."

Later, before his angioplasty, he told me: "The black bags are looking better all the time."

The angioplasty seemed to help his strength and breathing for a while. He went home. In about a week he resumed dying his slow miserable death.

On December 30, he called me and asked me to take him to the Emergency Room the next day. He would tell them that he thought he was having a heart attack so they would be sure to admit him. He wasn't. I guess he didn't think they'd admit him if he just recited his "regular" symptoms.

They performed heroic emergency surgery twice within the next week. Presumably he would have died after 3 more days at home. They took more colon and did another colostomy. He was on life support—puffed up with his mouth open and face distorted like road-kill on the shoulder of the road except with sterile plastic tubes everywhere. The only sign of life for the next week was the occasional shaking of his head from side to side; the nurse said it was because of the tubes in his throat but I wondered if he were shaking it "No," trying to tell me to start pulling plugs.

"Are you here to see Mr. Harvey? We moved him after he came back from his CAT scan. He's over there now." I looked behind me. He was still tangled up in a mass of wires and tubes but it looked like his eyes were half-open. As I got closer, I could see his eyes really were open and they looked up at me. Unbelievable!

I mumbled something perfunctory. I really hadn't expected this—ever. When I left him in the Emergency Room he had asked me to pick up some items for when he went home; I'd already returned them. Now he was smiling at me. I felt giddy. I laughed, "I can't believe . . ." I had to search for something to say, ". . . how much progress you've made . . . how much better you look."

"I mean you still look like hell . . . but it's better." By now he was laughing. No sounds were coming out but I could tell he was laughing and that it hurt.

I didn't stay long. I brushed my hand over his head and told him I'd be back, "Tomorrow." I couldn't wait to call friends. I'd been telling it like it was; I needed to tell it like it had become.

Unbelievable! In fact, a nagging doubt that maybe it should have turned out otherwise.

He hasn't been free of tubes and machines the past 5 months. There have been times when he improved followed by times when another heart attack or high fever took him back to Intensive Care. When he could still talk, he'd ask, "Am I taking 2 steps forward and 1 step back or 1 step forward and 2 steps back?"

Nobody can find the Living Will or Power of Attorney now; he hasn't filled in the new forms I got for him.

Not going to the hospital New Year's Eve would have saved a lot of suffering. What had changed for him by then for him go back?

I always try to ask him if he's okay with what they're doing. So far he nods his head yes. I don't understand why; I don't see any future for him. But I can't hope for him to die when he nods his head that he is okay with what they're doing. I can't hope for him to live either; when others do I get angry. Then I have to remember that just as ending it would have been, going on is his choice and I have to respect it.

Meanwhile, someone has used the bags for trash.

FR Burdett lives, writes, and walks the seawall in Galveston, an island off Texas, in the Gulf of Mexico.

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