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Barely Breathing

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my mother-in-law died, we had trouble finding a doctor to sign her death certificate. Due to changing Medicare doctors at the end of the year (the one she had been seeing was no longer seeing patients at her nursing home), the transfer to the hospital and then the transfer back in hospice status, all the doctors who had seen her recently said that they weren't in charge of her care at the time of her death. The new doctor had never seen her because of their vacation throughout that time period. While technically this wasn't a "discharge issue," it was an issue that no one addressed until after her death, when we couldn't get a death certificate for over a week because none of the doctors were responsible.

Barely Breathing

Michelle Brose

I was born with a rare progressive neuromuscular disease which causes generalized weakness and hearing problems. I used a walker and crutches as a child, a manual wheelchair at ten years, and a motorized wheelchair at age 16. Toward the end of high school it had started to affect my breathing muscles, and during my second semester of college a carbon dioxide buildup sent me into respiratory failure.

I was hospitalized and put on a ventilator, which had an inflated cuff around the trach tube that prevented me from speaking. I was suddenly only able to communicate by pointing to letters I had written on a card. My arm muscles also deteriorated at that time from the prolonged immobility, so I didn't have the strength to press a call bell, and was given a desk bell instead. I had just enough finger strength left to hit the bell or point to the letters if they were positioned close to my hand on my chest; if they were a hair's breadth too far away, I couldn't communicate. They had used an antiquated formula (originally developed for comatose people who don't need as much oxygen) to calculate the volume of air the

ventilator was giving me, so I was suffering from a constant feeling of shortness of breath, and had gotten pneumonia twice. Because of my trouble communicating, and knowing I was vulnerable to having the ventilator tubing fall off, I was placed in a room right across from the nurse's station.

I knew nothing about life on a ventilator back then, and neither did my doctors, social workers, discharge planners, et cetera. There were no support groups for people with my condition at that time, and I didn't know any ventilator users with other conditions that I could ask advice of. Once it was clear I wouldn't die, hospital and insurance administrators didn't know what to do with me beyond putting me in a nursing home. I was told that they couldn't discharge me to home because I was required by law to have 24/7 nursing care set up before I could leave the hospital, and that neither my private insurance nor Medicaid would pay for that. I was told that my only option was a nursing home, which they wanted me to hurry up and consent to. I didn't, for several reasons. For one, nursing home staff would not be able to "make changes", like upping the volume of air or switching to a cuffless trach so that I could speak again. Living the rest of my life in a nursing home, unable to move or speak or even get a deep breath, was unfathomable to me. Death would be preferable, I thought.

I'd also heard, from a couple of the better respiratory therapists there, that there was a doctor at a spinal cord injury rehab center in New Jersey who was doing great things with noninvasive ventilation. Noninvasive ventilation, through a facemask or mouthpiece, was not subject to the same regulations as invasive ventilation, even if your breathing was completely dependent on it. I wanted to try for it, but my insurance company didn't cover rehab. Because I couldn't speak and had no telephone in my room, my mom had to call and negotiate with the insurance company, but was unable to convince them to send me to rehab. I continued to refuse to consent to the nursing home, having heard from disability activists long before my hospitalization that no one can force you into a nursing home against your will, but that they can withdraw care.

It was the “they can withdraw care” part I didn’t fully comprehend. I thought that meant they would have to discharge me to home at some point. It wasn’t until one day one of the nurses whispered to me that I wasn’t making any friends in the hospital administration that I realized what was going on. When I asked her what she meant, she explained that not only did my insurance not want to pay for rehab, but they didn’t want to pay the hospital bill at all, because I was considered stable and should have been discharged long ago. I had trouble following the logic. How could they refuse to pay for what was at that point four months of hospitalization for someone who could no longer breathe without assistance?

Facing nonpayment of a very large bill, the hospital administration decided to hold a meeting to decide what to do about me. They invited my mother to attend as my representative, but I knew they would steamroll right over my sweet, placid mother if I wasn’t there. I reminded them that I was over 18 and legally an adult, that she couldn’t consent for me, and that they had to hold the meeting in my room. This was apparently an unprecedented request, but they could think of no reason to deny it. At the meeting I again refused to consent, pointing to each letter emphatically to get my message across. I agreed to work on convincing my insurance company to go off-plan and pay for rehab. The administration also wanted me to watch some video advertisements of nursing homes they had picked out for me, promising me the use of a big-screen TV to do so.

I started writing letters; to my insurance company, to the city and state governments, to anyone who might be able to intervene. And I dutifully watched the nursing home advertisements. One was particularly strange; it featured a stone-faced elderly lady supposedly using a ventilator that didn’t seem to be turned on. She sat, stiffly and unmoving, on the bed in a room beautifully appointed with Queen Anne style furniture and carpeted in pale blue. The next scene showed her sitting in a limo, dead-eyed and expressionless, while a chauffeur closed the door for her. The limo made its way down a broad picturesque boulevard,

trees covered in brilliantly yellow leaves. And then the lady sat frozen in a wheelchair on the porch of an elegant old house, at a small table set for Thanksgiving dinner, sharing an entire roasted turkey with one equally elderly friend.

I attempted to make sense of what I’d just seen. *Who eats Thanksgiving dinner out on the porch in November?* I wondered. And where was the supposedly required 24/7 nurse? Had I just watched a video of a genuine nursing home resident, or an actress? If she was an able-bodied actress, what was she basing her depiction of a ventilator user on . . . comatose people? If she was a resident, why did she look angry? Was she drugged? Was she being coerced? *Blink if you want to be rescued*, I wanted to call out to her. I decided the simplest explanation was best; the producers of video weren’t trying to give a realistic portrayal of life in a nursing home. They were trying to communicate the promise of luxury and care, using a simple visual language that people with diminished cognitive capacity could understand.

An administrator came back to speak with me the next day. “Well? What did you think?” he asked, smiling. I tilted my card towards him so he could see the letters I was pointing to.

“D-O Y-O-U T-H-I-N-K I-M S-T-U-P-I-D?” I spelled out.

“Stupid? No, no, what makes you say that? Why would I think you’re stupid?” He looked genuinely hurt.

“A L-I-M-O?”

“A limo? What do you mean?”

“You expect me to believe I’d go places in a limo?”

“Oh! Well, you’d have to pay for your own limo.” he replied.

“With the \$30 per month I’m allowed to keep?” I asked.

He gave up and left my room without another word, crushed that I didn’t like the nursing home propaganda. The next morning, they unceremoniously rolled the TV out.

Shortly after that (a couple of days later), I had a ventilator “pop off” where the tubing suddenly became disconnected in the middle of the night.

I wasn't all that worried at first; they were pretty good at answering the alarms promptly, and my nurse that night was particularly conscientious. But the minutes ticked by and nobody came into my room. I watched doctors and orderlies and CNAs walk by, and not one of them looked in. I began to ring my bell frantically.

Suffocation was surprisingly noisy. In addition to the usual *wooshes* and white noise from the ventilator, the loud beeping of the low pressure alarm was overlaid by the high-pitched ringing of my auditory nerves shrieking from lack of oxygen. My pulse roared in my ears as my field of vision shrank down to a tunnel and disappeared. I gave up on ringing the bell and pulled it close to my chest instead, hoping that my mother would see it and know that I had been calling for help. I didn't think I would wake up again.

The next thing I knew, I was on my back with the overhead light burning into my eyes. I opened them to discover I was surrounded by several people looking down at me with concern. I had soiled the bed while I was unconscious, and was now covered in a thick, gel-like sweat. I felt like death warmed over. I burst into tears, shaking from fear.

The nurse immediately told me what happened as the others filed out. She had been in an isolation room and didn't hear the alarm, and no one else had been sent in as was usual. Once she left the other patient's room and took off her protective suit, she heard the alarm and asked "Why is Michelle's alarm going off?" She ran to my room, discovered me unconscious and screamed "Code blue!" An orderly brought the crash cart while the nurse resuscitated me. By the time I woke up again, a small crowd had gathered, including the priest on his morning rounds.

But they did not call my mother. I kept asking the staff to call her and tell her what happened, but they kept saying things like "We haven't had a chance yet," and "we'll get to it soon." Finally, after another shift change, they relayed the message back that she said she'd be in to visit me at her regular time that night. *They didn't tell her what happened*, I realized. If I had died that night, they would never have told her the truth about how.

Sure enough, when she finally came to visit me, she was shocked when I told her that I had passed out and coded. All they had told her was that I'd had a bad night and was asking for her. I told her how no one had come to reconnect me, and my normally placid mother was furious. She stormed over to the nurse's station, demanding to know why no one had been sent to answer the alarm. No one could remember who was working or who was responsible for what. She was directed to the charge nurse, who was angry at my mother's question. The charge nurse put her hands up in a defensive position and shouted, "You need to face facts and put her in a nursing home! She isn't going to get the care she needs here!" My mother shrank back, petrified.

I was so chilled by the implications of that statement, that I couldn't sleep that night. I was so frightened there would be another *incident* that I had to remain vigilant. I just stayed awake with waves of pure fear rolling over me, my heart pounding. (At one point my heart rate was at 180 bpm, according to the pulse oximeter.)

The next morning a nurse came into my room with good news. A space had opened up at the rehab center I wanted to go to and they were letting me "jump the line." I could be transferred there within the next three days. But I still had to get the prior approval from my insurance, and get them to pay the hospital before I could be released. My mom yelled at the insurance company representative, "If she was stable then *why did she code!*"

"She coded?" the lady gasped. I was approved for four weeks of rehab on the spot.

I found out later from people at the rehab center that my nurse had called the administration there the day after I coded, telling them I wasn't safe and begging them to find me a spot before there was another *incident*.

Within an hour of being admitted to rehab, they were able to switch me to a cuffless trach and set me up with a Passy-Muir valve so that I could talk again. They increased my volume and discontinued the oxygen, so I no longer felt short of breath all the time. Soon they were able to train my mother on the ventilator, then wrote the orders to discharge me to home. I didn't have any home care at first,

so my mom quit her job to take care of me 24/7. It took six months, but I was finally approved to join a Consumer Directed Personal Assistance Program, under which I could train home health aides to provide the level of skilled care that I needed.

After that, I finished an Associate's degree from a correspondence program, then taught myself web design and coding. I started taking online courses in genetics, and realized some of my coding skills would be transferable to the field. Today I'm working on a Bachelor's in Biology at an Ivy League school, after which I hope to go to grad school for genetics. It pleases me to think that some of my classmates will become doctors someday. I hope if they're ever confronted by a case like mine, they'll think, "Well, there was this girl on a ventilator back at school, and she was able to live in the community. Why should this one have to go to a nursing home?"

Out With The Trash, Out With The Trash, Out With The Trash!

Samantha René Merriwether

That was no typo; my title was written correctly. After an injury occurs and a doctor treats you, it is critical to have appropriate discharge planning that fits your personal needs. Having one follow up appointment is necessary to ensure that the injury, which may have been emergent at the time, is later reevaluated from a different perspective to prevent future problems. But too often follow up appointments are swept under the rug because it is perceived as a nuisance to provide aftercare. Not having that opportunity in multiple situations left me with a lifetime of irreversible damage. If only one mistake had been made, I might be more likely to brush it off; but somehow the medical community has blacklisted me.

Although being naïve contributed to my first horrific experience with the health care system, it was no excuse for how I was treated. I was a passenger

in a car accident when we were rear-ended by a truck. Sitting behind the driver's seat, the headrest was dislodged and rammed into my stomach. While under the knife, surgeons removed car parts from my stomach and made executive decisions without waking me up to make any informed decisions. When they were "done," I was left with a feeding tube in my stomach and a treatment team that consisted of a surgeon, an internist, gastroenterologist, physical and occupational therapist (P.T. and O.T.), and a nutritionist.

During my month long stay, most of my time was spent in bed. And when I began to walk small distances, they felt it was a qualification to be discharged and gave me a 24-hour notice that I had to leave. In my mind, I thought that further physical and nutritional counseling was necessary to provide me with an adequate stability to go home. I tried to explain that the eating disorder (ED) I had for years combined with the feeding tube seemed insurmountable to me. Unfortunately, what type of support I had after leaving there, was not any of their concern.

I used the feeding tube as an excuse not to eat. Skipping and splitting doses was not unusual for me. Ironically, I fainted in a grocery store less than a month later. The manager happened to see my nutritional "hip pack" with the feeding tube supplies and helped me into their break room to allow me to rest, as I refused a call to 911. I took an extra injection of calories and finished my shopping with some help. As soon as I got out of the store I received a horrible message. A hospital representative called me in to have the feeding tube removed. I was floored. I was at the end of the "recommended" amount of time to transition from liquid to solid foods. I was anything but prepared to safely manage my nutritional needs. When I got into the hospital for my pre-op testing, it was noted that I was barely stable enough to go through with the procedure, but the tube was removed anyways; against both my wishes and the nutritionist's. The reality was I was being put "out with the trash!"

I tried to continue to live my life, but I lost my therapist, transferred colleges, and got hit by another medical emergency. That emergency was