

Right Brain: Not on my watch

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These sorts of things always happen on a busy call night. Those in careers other than medicine call it superstition, but physicians know it is fact: If ever there is a time for something to happen, it will happen when you are alone, tired, and overwhelmed with work while on call.

And so it was the evening I first met patient EG. Already several consults deep on the wards, and now in the emergency department (ED) for 2 acute strokes, I was sitting at a desk in a workroom, just behind the main hub of ED activity. Admittedly, it was a poor choice of seating for an on-call resident, leaving one visually exposed and too easily available for any and all possible non-neurology consults, but it was the only free computer with a nearby phone, and I was awaiting a call from the attending. As I read through the available records of the 2 stroke patients, searching for relevant history, I almost missed the casual passing remark by an ED resident as he walked by, “We have a patient well known to Neurology in Room 12.”

“Oh?” I said. “Is it urgent? Because I have these 2 stroke patients, and ...”

“No, it’s not urgent; she’s already been unresponsive for hours,” the resident said flatly.

I was immediately concerned. “You mean she has been sedated?”

“No, we didn’t sedate her. I think she has seizures. This is the fourth time she has been here in about a month.” Like any self-respecting neurologist, I was simultaneously concerned, intrigued, and skeptical, and quickly got up to go see her, leaving the waiting phone to which I had just paged my attending.

I walked over toward the ED room, taking it all in. There was a gentle-looking middle-aged man standing on the right, leaning against the wall. He was staring at the bed, at a younger curly-haired petite woman lying flat, motionless, in the bed. After introductions, he explained that he was the patient’s father. I listened to him recount the evening’s events, followed by last month’s events, followed by last year’s events, all while frequently glancing at the

monitor to reassure myself that her vital signs were stable.

While I was examining the patient, trying unsuccessfully to elicit some sort of reassuring response from her—anything—her father handed me a piece of paper.

“This is her DNR/DNI. She had it notarized 3 days ago.” I stopped and stared at the document. It did not make sense to me—he had already told me that she was barely in her 40s, and that she had a teenage daughter. She did not have a terminal condition as far as they knew, and he assured me that she was not suicidal.

I explained my concern—what if she had a reversible condition, but accidentally aspirated or otherwise lost her airway? He explained, “She’s been through so much, so many of these episodes, so much testing over the last year ... that she decided if God wants to take her one of these times, she is at peace with that.”

My heart sank—I was not at peace with that, not at all. I was cautious not to voice my bias—as we are all trained to do—and did not say what I was thinking: it is acceptable to have a DNR/DNI because of terminal illness, religious beliefs, even old age ... but not because of intermittent unconsciousness. The medical system had failed her. She had been to 6 hospitals, had hundreds of tests, and was left with lots of results, but no answer, and now, it seemed, no hope. I did what was requested that night—I admitted her, placed DNR/DNI orders, and ordered all the supportive care measures and noninvasive, nonsedating empiric treatments I could think of, all while silently telling myself, “Not tonight. Not on my watch ...”

EG came and went a few times over the next several weeks. We came to realize that her spells were fairly stereotypical—she would become unresponsive for 1–2 days, spontaneously wake and be acutely agitated for about half a day, and then return to baseline. In between spells, she could be asymptomatic for anywhere from 1 to 30 days.

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That encounter was the beginning of an obsession—not just for me, but for all the neurology residents. We collectively lost hours of sleep researching and pursuing answers. I spent hours reading about possible diagnoses in the dark on my smartphone, typing with one hand while holding my sleeping baby daughter in my other arm. We distributed a multipage summary of her medical history to our faculty, to ensure that everyone was aware of her case, and to solicit ideas. We often worked in teams to admit her, to stabilize her, and to initiate time-sensitive tests immediately at the onset of a spell. In the resident workroom, taped above the computers, hung a “Miss EG to-do list.” With each admission, there was an increased sense of urgency, a fear that one of us would be on call when she would have an aspiration event or a cardiac arrest, and we would have to stand by, helplessly.

Each of us had a different theory—Ondine’s curse, porphyria, seizures restricted to the brainstem, a late-onset metabolic disorder—the list was long. We often questioned our own examinations. The psychiatric overtones were obvious, and there was always a temptation to write off all of her episodes as psychiatric—catatonia, for example. We analyzed her history and her behavior in detail. She did not always behave and respond as we thought she should. She was not always as concerned as we thought she should be. Was it an overdose, or even poisoning? We convinced ourselves that she demonstrated features of *la belle indifférence*, but then felt guilty for judging her reactions to a situation we could not imagine, and redoubled our efforts to find the cause of her spells. Perhaps, we thought, the pathology itself caused behavioral changes as well as unconsciousness, reminding ourselves that psychiatry and neurology are rarely as clinically distinct as the medical system designates the specialties. Perhaps we subconsciously wanted this disease to be some sort of psychiatric condition, so we would not have to admit that we could not diagnose a neurologic problem. Ultimately, however, this was not about our own egos or reputations—this was about a dangerously ill patient, and we would want an unbiased, dedicated, and determined physician if the tables were turned.

We decided the answer would be found in a thorough review of her records: 6 hospitals, 2 private physicians, and over 300 pages later, we felt certain that we had eliminated several diseases from consid-

eration, and that a few possible conditions required further investigation. We ordered some more tests of our own, gradually, as EG reluctantly permitted. We slowly gained her trust. Yet several more tests and a few false-positives later, we still had no answer, though we had more pieces of the puzzle—she was in burst suppression during the spells, and her toxicology screening was repeatedly negative. Her repeated examinations showed her to be flaccid, with only paradoxical responses at best to cold calorics and smelling salts.

I—we—spent many nights worrying that she would die of this disease—a young woman, with a teenage daughter of her own. I had never before struggled so much with a disease process—perhaps it was the unknown—not knowing if it would progress, or if it was ultimately terminal. I found myself so much more dependent on having a name, a label, for the process, than I had ever been. The disease was so dramatic in presentation, taking her from normal to comatose with no warning, almost mocking in its behavior, as if implying, “Could I be any more obvious? Look, here I am again—want to take another shot at figuring me out?”

With each subsequent discharge, the emotions became more raw: embarrassment, pride, frustration, disappointment, humility, and determination. There was a sense that the disease was winning, and the “to-do list” was getting shorter.

Ultimately it was a rotating medical student and a new attending on service who revisited the basics—reviewing her medications—and we planned to test for specific medication toxicities not routinely available on toxicology screening. On the next admission, she had toxic levels of baclofen in her blood and urine. She had been prescribed the medication years ago, but the spells had only started in the last year. Since enforcing the complete discontinuation of baclofen, she has had no further episodes. And I am left with the ongoing struggle of just how much to trust our patients over our instincts.

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DISCLOSURE

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