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Lost to Follow-up

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Miriam Stiller stooped over, even while lying in bed. At 62, she was young for dementia and had thick gray hair cut in a short, undifferentiated style. The efficiency of her haircut implied a nonsensical personality. Remnants of it showed through her confusion at times, like brilliant fish surfacing in murky water. She lay in bed, head and shoulders lifted off the pillow in a stiff, horizontal genuflection. Despite the immobility of her body, or maybe because of it, her eyes were restless. They locked on me when I entered the room.

“Help me help me help me I gotta get up I gotta get up.”

Her mouth moved little as she spoke. The alarm came not in the volume or even the content of her speech, but in the peculiar disparity between her immobility and the fast, small rush of words with no space between them. No capitals, no periods. Just a tumble of words going nowhere. The resident and I exchanged glances across her bed.

“Oh, God,” we thought. “What are we supposed to do with this?” We may even have said it out loud. We went back and reviewed the chart. She had been demented and incontinent for a year, unable to walk for 5 months. Her Mini-Mental State Examination score 2 years ago was 25 of 30. Her CAT scan showed ventriculomegaly. People had been thinking about normal pressure hydrocephalus (NPH) for 2 years. She had even been referred to Neurosurgery Clinic, but the appointment never occurred and no one noticed until a year later. She had been slipping down the dementia hill for a long time and was now reaching the bottom. Even if she had NPH, it was probably too late to shunt her and achieve recovery.

Normal pressure hydrocephalus is a theological concept. You either believe in it or you don't. The difference between believing and not believing is personal experience. If you've seen a patient recover with shunting, then you believe. If you've read about it in textbooks and papers but have

only seen shunt infections and subdural hematomas, then you don't believe. I was a nonbeliever. I had prayed to the NPH god more than once and received only one answer: “Your hope was naïve. Now look what you've done.”

We returned to Miriam's room. She was awake, alert, oriented to self, 1988, hospital. She picked her nose constantly, first with one hand, then the other. She followed no commands. Registration 3/3, Recall 0/3. Speech was festinating, monotonous with neologisms and perseveration. Mini-Mental State Examination score was 6/30. Strength was normal, but she was spastic in the lower extremities with upgoing toes. Her MRI showed ventriculomegaly with mild atrophy and periventricular low signal. There was no aqueductal flow void. The scan was consistent with NPH, but it was nonspecific. Our plan was a high volume tap. We rolled our eyes even as we wrote down the words.

The next morning on rounds I approached her room with a vague feeling of dread. I always feel this way when the diagnosis of NPH comes up. I feel NPH in the pit of my stomach. It's a different feeling than with, say, amyotrophic lateral sclerosis (ALS). The feeling with ALS is also in the pit of your stomach, but it is more like helplessness or guilt. The patient is dreadfully sick and you know it. You usually know it the minute you hear the story over the phone, or when you see the fasciculations or certainly when you hear the fibs during the EMG. And the disease is in charge from then on. Your role is supportive. It is difficult but not risky. You are an onlooker to the inevitability of decline and death. In NPH, the physician is the pivot point. The diagnosis is seldom clear. “Ventriculomegaly out of proportion to cortical atrophy. Clinical correlation is necessary.” Well, you ARE the clinical correlation. There is nothing firm to grasp: no DWI, no 3 Hz spike-wave. No fibrillations.

The next morning, Miriam was the same. I fumbled a discussion of NPH with the residents and students. My uncertainty glared. The resi-

Though the names have been changed, the patient and her family gave permission for publication of her story as written.

dents tried the first lumbar puncture and failed. Neuroradiology did the high volume tap but there was no improvement. A second tap was necessary. I decided to do it myself.

Miriam didn't move her legs much but she moved her arms and her mouth a lot. She might require "moderate sedation." We sent for a monitor, placed an IV, and brought several doses of Versed to the bedside. Knowing the tap would be difficult, we placed her upright over a bedside table. All the while she shouted:

"ImgonnafallImgonnafallImgonnafall."

The team, now a jumble of residents, nurses, and students, coaxed and reassured her into place. The image of her back, spreading before me, doughy and pale, stays like a snapshot in my head. Her skin was sallow in daylight that came through the window. The light inspected her back. It took note of a mild kyphosis and of several skin tags. It observed that her skin was remarkably smooth and youthful for a woman in her 60s. It touched her lightly, reassuring. I was grateful for the daylight. It tacked us to reality, to the flesh, to the moment.

My arms were bare and I was vaguely self-conscious in front of the team. The focus was on Miriam and keeping her calm. We had given her one dose of Versed, which seemed to have no effect. She was demented but still witty and she frequently said things that made us laugh. As she rambled and shouted, each of us cast about for a question or a comment that might focus her for a moment. One would offer a response and Miriam would take it, but its effect would last only for a few seconds, then another distraction would be necessary. We went from one fragment of sense to another. She was crossing a creek and afraid of the water and our words were like stones for her to step on.

"Do you have any children, Miriam?"

"TwobabiesIhavetwobabies. Helphelp."

"What are their names?"

"Imgonnafall, Imgonnafall."

"No you're not. We are holding you. Where do you live?"

"Syracusewheredoyouthink?"

"Did you grow up here?"

"DoIsoundlikeI'mfromSyracuse? Queens, I'm from Queens. Helphelphelp."

I worked steadily at the tap. I kept passing the needle nearly to the hub without much resistance, but no CSF flow. Somehow the topic of ice cream came up.

"I love ice cream," said Miriam in her Queens accent.

"What flavor?"

"Chocolate."

"Chocolate? Do we have some chocolate ice cream?" I asked.

"I think so," said the nurse.

"Get some."

Shortly, she returned with two small cups of chocolate ice cream.

"Feed it to her," I suggested. "It's safer than Versed."

So while I worked at the spinal tap, while the room buzzed with activity, the nurse spooned chocolate ice cream into Miriam's mouth. Two cupfuls. Shortly thereafter I felt the telltale "ping" of needle passing through the ligamentum flavum and the spinal fluid crowned at the needle hub, a swirl of blood across its forehead. There was general celebration in the room. Miriam understood enough of what was happening to celebrate with us. It was more like Thanksgiving dinner with the family than a medical procedure: the residents bending close, petting and pulling and coaxing, like grandsons with a cantankerous grandmother. The students chirping suggestions, their eagerness and optimism glowing. Lumbar puncture under sedation with chocolate ice cream. The scene hangs in my memory like a portrait, half Rockwell, half Larson, a glimpse of how medicine can be if we let ourselves be foolish.

The tap produced no useful result. We were not doing lumbar drains at the time so we had done what we could to salvage her, short of a ventricular shunt. There was no indication that a shunt would help. She was severely demented, a poor prognostic indicator. The only sensible choice was to send her back to the nursing home. But I was restless.

The next day I approached the chairman of Neurosurgery. He is an acerbic man, balding and grizzled, who suffers no fools. Yet his face has an inquiring, cherubic quality that divulges a kindness he is bashful about. I have always trusted him. I told him about Miriam.

"Huge ventricles, no atrophy, spastic paraparesis, but the taps did nothing."

"There are hundreds of people like this, rotting away in nursing homes," he growled out the corner of his mouth. "If she were my mother. . ." He paused. "I'd shunt her."

Miriam's brother was a bright, sensible man, who visited frequently. He noted no improvement after the tap, except that she had heard his voice outside her room and asked for him by name, something she had not done in months. Miriam

had been an English teacher. Her cognitive decline was made particularly cruel by the height from which her mind had fallen. This grieved her brother greatly and made him willing to take a risk. The neurosurgeons talked with him and we decided to proceed with the shunt.

I left the ward service within a day or so and did not see or hear about Miriam for months. When I thought about her, I mostly felt shame, sometimes a flame of hope. Then one day, 6 months later, I described her to a friend: the tap under sedation with ice cream and the foolhardy shunt. Following our conversation, I got into my car and drove to the nursing home where she lived.

Tentatively, my car climbed the driveway to the nursing home. It was snowing lightly, and winter-bare branches scratched at the gray sky. Approaching the top of the hill, I saw a new, yellow brick structure that was clearly built for well-to-do seniors. Yes, Miriam could live here. I crossed the lot and entered through a lofty archway. The foyer rose two stories, feigning elegance. Hospital hallways stretched away from it in two directions. Voices tried to echo, but they were arrested by the soft, patterned carpet.

"I'm looking for Miriam Stiller. Does she live here?"

The two receptionists stopped talking and looked up at me.

"Miriam? Oh, yes. She's out smoking." One pointed toward the back of the building.

Smoking? I thought. Six months earlier, she would not have been able to hold a cigarette.

One of them led me along carpeted hallways, past a sitting room and vending machines. We turned and turned again. The carpeting gave way to linoleum. A lone custodian pushed his mop listlessly, looked up, and studied me as I passed. After a long while, the receptionist stopped and pointed at a doorway. Through the glass I could see a cluster of people, seated and laughing. By their blue, I knew some were cleaning staff; by their white, I knew others were nursing staff. I pushed the heavy metal door open; heads turned and conversation ceased. I scanned the crowd. There she was. There was Miriam. She sat, gray haired, in a wheelchair, looking straight at me. She held a burning cigarette in her right hand. I looked at her hopefully, but my gaze came back empty.

"I'm Dr. Bradshaw, Miriam. I've come to visit you. Do you recognize me?"

"No. Dr. Bradshaw? Hullo! How are you!?" She waved wildly with her free left hand. "C'mere! Want a cigarette?"

Back in her room, I sat on her bed and we visited for nearly an hour. Pictures of her sons lined the room and she told me about each one.

"He's brilliant, a genius," she said. "But lazy. That one is a good boy. Those are his two girls. Beautiful, aren't they?"

She was beginning to take steps using the parallel bars. She had no recollection of her hospitalization. She was completely unaware of her own dramatic story. I told her about it and she listened, but the miracle of it didn't seem to catch hold of her. Instead, she told me about her numb hand and asked me to help her with it. We finished talking and I went to the nurse's station. Surely, they would be amazed. They had seen her before and after. But they weren't.

"She's very manipulative, you know," they said confidentially.

The next day, back at the hospital, I looked for the residents who had helped me take care of her and I told them eagerly about my visit to the nursing home. They looked doubtful, unimpressed. Three times I scheduled a follow-up visit for Miriam at the clinic. The first two times she "no-showed." I was determined that the senior resident should see her once before he graduated. I called the clinic one more time and scheduled an appointment. I put the date into my PDA.

The day arrived. At 3:30 I saw her initials on the white board: "M.S." I collared both residents and we entered the room. Miriam sat slumped in a wheelchair, her face lax with sleep. She was wearing lipstick, carefully applied. We sat down in front of her and she lifted her head, looking dully from one of us to the other. During that lapse of seconds, my mind veered from "Her shunt has failed, they'll never believe me," to "She's in there, I see it."

"Dr. Bradshaw, Dr. Ali! How are you?"

We talked for about 15 minutes. She still had no recall of her illness. Her right arm had been quiet at her side throughout our exchange. Casually, she mentioned that her breast cancer had returned and invaded her brachial plexus. My mind shot back to our interview at the nursing home when she complained about her right hand. I was crushed. All of Miriam's struggles had come to this cruel, ironic anticlimax. I did not know what to say. But Miriam retained a steady nonchalance about her recurrent cancer.

"They're giving me radiation," she shrugged.

Two weeks later a card arrived in the mail.

"Dear Drs. Bradshaw, Ali, and the rest of the Neurological team. Thank-you for 'playing God'

with me on the shunt operation. Words cannot express how thankful I am to be able to gravel with adversity as it comes and goes, day in day out.” She was glad to be present in her struggle, though life still offered her no ease or promise of an uncomplicated future.

After that I visited her at the nursing home from time to time, taking chocolate or photographs or flowers. One day she showed me a picture of herself, taken 10 years prior, with raccoon eyes. Finally, I understood the source of the NPH.

To the end, she was grateful. It was hard to understand her gratitude for having been brought back to a life of pain. She lived those days fiercely, even violently. She leaned into her small life at the nursing home and somehow made it large. Standing graveside with her family and friends, it seemed that those days had been a gift to us, to her brother, to her story. I am grateful to have known this woman, a rare and lively creature, who emerged from darkness for a time, and enjoyed the light, shimmering low and silver, at the end of day.

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