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Wastebasket patient

Pale and silent, William slumped in his wheelchair. His features were coarse: heavy eyebrows, soft chin, fleshy nose. His head tipped to one side and nodded gently, his limbs inert.

"William?" I ventured. "How are you today?"

No response. His sister, Jacqueline, spoke instead.

"William has been going downhill for years. I've taken him to a lot of doctors and they say it's his cerebral palsy getting worse. But I'm a nurse and I know that cerebral palsy doesn't get worse." Jacqueline spoke earnestly, straight blonde hair framing her placid face. Her full cheeks shone pink with feeling. The only surviving family member, she was his passionate advocate.

"He can't stand up anymore. He used to like to go for rides with me and get coffee at Burger King. I can't get him into the truck because he can't stand to transfer. He used to have a paper route at the nursing home, but he stopped doing that." Though her voice was feminine and delicate, Jacqueline's tone was urgent, her frustration evident. When she spoke directly to her brother, her eyes and voice softened.

"You want to get back to your paper route, don't you, William?"

There was no discernible response.

I was seeing William at the request of my friend and coworker, Tommie, a nurse practitioner. When Tommie first approached me, I resisted. I was stressed, and William's condition, intellectual disability and seizures, was hardly my specialty. A low baseline sliding lower. Can't take a history or do much of an examination. Too many interacting factors confusing each other, all chronic and unfixable. What's more, I had no idea what to do with him. Often, doctors resist new consults out of unacknowledged fear of incompetence and failure. I was no different.

"I'm a neuromuscular specialist. I know nothing about mental retardation. What good can I do him?"

Tommie persisted. "I don't know anything about it either, but Jacqueline asked us to see him. She works at our hospital."

Hearing this, my resistance melted. We scheduled the appointment.

In the examining room, we learned more about William's history. He had been a very large, full-term baby, whose mother had labored at a small community

hospital in rural upstate New York. At that time, there were no emergency room doctors. Nurses held the front line, and the doctor was called in from home, if necessary. William's labor went on for 20 hours. He was in distress and should have gone to C-section. The doctor who was called happened to be sleeping in the hospital that night. But he was drunk. So the nurses delivered William vaginally, with high forceps. The baby was blue, and the family was told that William would either die or be blind and never walk. Despite these dire predictions, his family took him home, determined he would lead as normal a life as possible.

At age 1, the seizures started. The family learned to treat them at home. Jacqueline recalled a huge orange bottle of Dilantin sitting next to a large bottle of red phenobarbital in the refrigerator door. If there were 3 seizures in a row, they would take him to the hospital, where the nurses would place a 4 × 4 gauze over his face and drop ether onto it with a medicine dropper until the seizures stopped. They called this "drop ether." William would be sedated and have headaches for a day or two. His mother, a tiny woman made of "stone and wire," sat at his bedside, placing cold washcloths on his forehead, rubbing the muscles made sore by relentless seizures.

Despite his epilepsy, he became a happy, active boy. His motor and cognitive milestones were delayed, but he learned to walk by age 2. He could recognize numbers and letters, and started public school. One day, on the bus ride home, a boy commented to Jacqueline, "William just sits in the back and colors all day," a detail Jacqueline reported to her father at the family supper table.

Their father was the family anchor, tall, with a thick head of blue-black Irish hair and cobalt eyes. To him, his family was everything.

"What? Coloring in the back of the room?" A huge hand came down on the table, startling the silverware. "Like hell." His mother looked up and her face softened. Within a week, William was enrolled in a special educational program, where he remained until he graduated at age 21.

In the clinic, Tommie and I examined William. He was not oriented. He recognized his sister. He followed a few simple commands slowly. The

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examination was limited by his debilitated state. He appeared to be weak, unable to extend his arms or legs to test for ataxia. Reflexes were absent and he could not stand. It was a case of so much dysfunction and pathology that individual signs and symptoms, the backbone of neurologic diagnosis, overlapped and obscured one another. I really had no idea what was wrong. He had proximal weakness. Myopathy? He was areflexic. Neuropathy? His attention waxed and waned. Delirium?

"Let's get an MRI," Tommie suggested.

"Why? What, specifically, are you looking for?" I asked, irritated. Tommie flew on instinct and was often right. But it bothered me when she couldn't support her hunches with scientific rationale.

"I don't know. Just to see what his brain looks like."

For lack of a better idea, I agreed.

The phenytoin level came back therapeutic. The CPK was normal. Then the MRI report arrived. Tommie and I pulled up the images. I had never seen anything like it before or since: William's cerebellum looked like a tree in winter. Profound cerebellar degeneration caused by 35 years of treatment with phenytoin. Tommie would call it a "bingo." So simple. So obvious. Overlooked for decades and passed off as a low baseline just slipping lower. I called Jacqueline and explained. We tapered the phenytoin and started carbamazepine.

Within a few weeks, Jacqueline called, elated. William was much better, sitting up straighter, mentally brighter. He recovered his slow, winning smile and eventually resumed his paper route.

Every Valentine's Day, Tommie and I each get a card, signed by William. Jacqueline repeats over and over that we saved her brother's life. I cannot reconcile these things: a simple diagnosis rendered grudgingly, a simple treatment, a limited recovery within the scope of a limited life, and gratitude that seems excessive for what we accomplished.

I feel like a cheat.

William was a "wastebasket patient," a person with severe disability, a long, complex history, and a slow decline, all viewed through the small peephole of an office visit. I tell my medical students that if you want to see the fundus, it's like looking through a peephole; you need to get your eye up close to it and get the best view of the other side. In the fundoscopic examination, the other side is the retina. In the office, the other side is the patient's life. Even getting close in the office (taking a thorough history, asking about details of everyday life) provides a limited view. We see patients like this all the time, especially in the emergency department, brought in from a nursing home with delirium or seizures.

"Seventy-eight-year-old nursing home resident with dementia..." Instantly our interest and our investment drop to nearly zero.

"Let's load her with Keppra and she can go back tonight."

"Twenty-three-year-old with developmental delay and seizures admitted with 5 seizures in a row." We address the immediate problem and fulfill our obligation without getting too close to the peephole.

"Forty-five-year-old man with lifelong cognitive impairment and seizures with a general decline in function over years..." A wastebasket patient. There's almost no point in getting close to the peephole. What's to be gained? Can we reverse the cognitive impairment? Cure the seizures? Arrest the decline? It's painful to look into those lives and suffer with those patients and their families. And it's painful to feel helpless.

We learn this habit of dismissing cognitively challenged patients or patients with dementia during training when the onslaught of patients day after day, sometimes 24 hours/day, is just too much to manage. Chronically overwhelmed, we learn to conserve our energy for the cases where we think we can make a difference. We conserve our energy so that we can keep going at all. Wastebasket patients fall to the side. The precious energy required to improve their seemingly hopeless situations seems foolishly spent.

I visited William at his rehabilitation facility recently. For years, Jacqueline had described the place as her brother's home. She spoke of his friends and the staff who love him, of his activities and the special things in his room. When I walked through the sliding doors, the institutional odor washed over me. Dated plastic and polyester furniture dotted the foyer. A woodgrain desk from the seventies stood watch over the entryway. Lunch lingered in the air. William and Jacqueline met me in the lobby. We took the elevator to his room, which was lined with photographs.

"Thaattss my hhoouusse," William drawled shyly when Jacqueline indicated a charming white farmhouse with gingerbread under its eaves.

"Who's this, William?" his sister asked, pointing to a picture of William being bear-hugged by a hale young man.

"MMMiiikke."

"Right! Mike was one of William's therapists. He was so good with William. Mike used to take him for ice cream and taught him how to throw horseshoes from his wheelchair. William got to be pretty good at it." One small black and white photograph with crinkled edges showed a large man with a fine, straight nose holding an infant in the crook of his elbow. Father and son regarded one another quietly.

Jacqueline drew my attention to a photograph of a blond boy of about 6, his hair cut in a Dutchboy. The

boy sat on the back of horse. A teenage girl holding the reins squinted at the camera.

"Who do you s'pose that is?" she asked.

"William and you?"

"Yup."

As I took this tour through William's history, it dawned on me just how far and how long he had fallen due to medical neglect. This boy rode horses once. This boy ran. Over the course of his early life, his motor skills deteriorated in parallel with the death of the Purkinje cells in his cerebellum, one by one. One by one, those precious skills that the medical staff said William would never acquire disappeared. No one but his family noticed.

We start out in medicine wanting to help, believing in that soft ideal of altruism, feeling deeply the suffering of our patients. But medicine is brutal to its own. There are too many needs and too few hours. The caregivers' well-being is pitted against the patient's well-being. So we learn to survive by pulling in the welcome mat to our feelings and replacing it

with a sign saying, "The line forms here." It is the only practical way to manage an often unmanageable situation. Wastebasket patients always go to the end of the line.

What William and Jacqueline taught me, what every patient with severe disability and their loving families teach me again when I pause to notice, is that small functional changes can transform lives. To the casual observer, our intervention with William did not make a visible difference. To William and his sister, those small improvements, the head held straight, the twinkling eye, the sly humor, the paper route, were life-changing. When such a patient and his family presents hoping for help, the energy required to respond to those "small" complaints is not so very large. And the solution may be simple. The physician's duty is to give credence to the family's concern without judgment, with a kind of innocence and trust, and to understand that a patient and his or her family, already devastated by illness, need more help than most, not less.

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