# Medical Mystery, Medical Humility

"To be a good doctor, sometimes you must envision yourself as slightly stupid." When a physician friend told us this after our 9-year-old, [redacted], mysteriously got very sick, the thought was hardly comforting. After all, good doctors are supposed to have answers to medical problems. But when various specialists were stumped by our daughter's condition, we gradually came to understand what he meant.

Our learning experience began when [redacted] became listless after a bout of vomiting that we assumed was caused by a minor, school-acquired virus. Her continued vomiting quickly dehydrated her, causing her to be hospitalized twice in the next few days. After her second return home, when she finally seemed to be improving, she was hospitalized a third time.

[redacted]'s third trip to the hospital was by ambulance. She complained of cramping in her right hand and, shortly after vomiting again, she shook violently for a minute or more and became unresponsive. Delirium and screaming soon followed. She was unable to complete sentences, and most frightening of all, she could not see.

An emergency computed tomography scan was normal. A few hours later, [redacted] regained her sight and speech, though she still complained of stomach and head pain. Tests of blood and spinal fluid showed no signs of bacterial or viral infection. This baffled the doctors, given that other markers in her blood pointed to an infection. However, a wide array of tests, from Lyme disease to tuberculosis, eventually also came back negative.

[redacted] was placed in a pediatric intensive care unit while we spent a sleepless night in a hospital waiting room. She had been an energetic child, creative and athletic, inventing impromptu song-and-dance routines and periodically running a profitable lemonade stand. Suddenly, here she was, gravely ill, though no one in the parade of specialists who visited her over the next few days could make a diagnosis.

Our daughter lay in a hospital bed, padded with foam on the sides to prevent injury from another possible seizure. She drifted in and out of consciousness. We remained at the hospital. During the week that followed, [redacted] briefly improved before her headaches became increasingly painful and her lethargy worsened. Our pediatrician looked into our anxious eyes and gave us his report.

"We just don't know," he said. "We'll have to wait for other clues. Sometimes we never completely solve the mystery."

Many aspects of life are uncertain, but medical mystery involving your child is surely among the most harrowing. We wanted answers, and yet here was a highly respected pediatrician with more than 40 years of experience who refused to engage in the false comfort of speculation, even as the parents of a sick 9-year-old urged him to do so.

Our daughter's illness became the subject of considerable discussion by the hospital's interns and residents. Was this some rare illness or merely an unusual presentation of a more routine one? After reaching a dead end, the team of doctors decided to return to square one, subjecting [redacted] to more tests for a second time. As her hospitalization dragged on, we were simply parents living in the moment, tailing the gurney as it whisked our daughter down a maze of unfamiliar halls.

Follow-up bloodwork finally provided the first solid lead to a pathogen. The doctors called it *Mycoplasma pneumoniae*, which, they told us, is actually quite common. However, the symptoms are usually so mild that few realize they have it, thus its nickname "walking pneumonia."

What puzzled the doctors was how the mycoplasma, which is usually limited to the respiratory tract, had spread to [redacted]'s central nervous system and swelled the lining of her brain. None of the doctors had ever encountered this before, but they now had a diagnosis to explore: mycoplasma-induced meningoencephalitis.

In order to probe more fully, any investigator must be both skeptical and curious. Jerome Groopman, in his recent bestseller, *How Doctors Think*, suggests that doctors don't doubt themselves enough. He cites studies showing that, after listening to a patient's symptoms for an average of only 18 seconds, "a doctor will interrupt, having already formulated his or her diagnosis." This, he claims, probably contributes to an error rate in diagnoses estimated at 10% to 15%, and half of those are said to result in significant patient harm. We should have been grateful when [redacted]'s doctors acted without snap-judgment bravado. But we, too, hoped for clarity and for the quick cure that plays so well in fictional, hospital-based dramas.

There was no quick cure for [redacted]. Indeed, there were immediate problems with her tentative diagnosis. First, the bloodwork only *suggested* a past mycoplasma infection—there is still no standard diagnostic test to detect the infection. And, because the infection is so common and often harmless, its detection in [redacted] would not necessarily mean it was causing her illness. Finally, the doctors wondered whether our daughter's illness might be the result of multiple infections working in tandem. The medical mystery remained.

Our pediatrician prescribed an antibiotic, moxifloxicin, in case what [redacted] had was indeed a mycoplasma infection. Nurses administered the drug to her intravenously, along with fluids and nutrition. Even after the antibiotic was given, there was no noticeable improvement in [redacted]'s condition as she began her third week in the hospital.

We delved into articles on mycoplasma, trying to bypass the heavy medical jargon and emerge with some understanding of [redacted]'s possible illness. We learned that less

 

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than 1 in 1000 mycoplasma infections results in central nervous system complications, although children under 10 years old are disproportionately affected. Death is rare, but severe after-effects, such as mental retardation, epilepsy, and visual impairment, are more common.

Oddly enough, [redacted]'s medical team ultimately came to doubt that mycoplasma was, in fact, a direct cause of her suffering. In yet another unexpected turn, the doctors thought it more likely that the mycoplasma caused an adverse immune reaction after infecting her. Instead of attacking the mycoplasma, her immune system attacked her own brain tissue, perhaps confused by similarities in the cell membranes.

The senior infectious disease specialist on the team found this explanation the most plausible because it rested on one bit of proof: [redacted]'s blood serum had tested positive for what seemed to be a recent mycoplasma infection and autoimmune activity. Furthermore, he believed that mycoplasma infection by itself was unlikely to have made our daughter as sick as she was, but this conclusion also was tentative.

If an accurate diagnosis points to a cure, the ambiguities in [redacted]'s diagnosis carried over to her treatment, which also had an element of educated guesswork. Assuming that [redacted]'s illness was an autoimmune reaction, then the antibiotics she received had been useless. In their place, the doctors tried a regimen of steroids to reduce the swelling in her brain. The efficacy of this treatment had not been clinically proven, but the medical literature reports that it has worked in some cases.

When [redacted] began to receive steroids intravenously, her pain decreased. Slowly her strength returned, and within days she was able to get up and walk around. During her fourth week in the hospital, the steroid treatment was tapered to a point where she was well enough to finally go home.

Even as we left the hospital, our pediatrician surprised us one last time by announcing that [redacted] may have recovered entirely on her own, without any medication. How uncanny that the same uncertainty that existed during her diagnosis and her treatment also remained in her recovery. But by this time the doctors who treated her had taught us to be more comfortable with doubt, and that a physician who acknowledges his or her limitations is far preferable to one who presents a façade of omniscience.

[redacted] is better now, and despite the fear we faced, she has had no observable after-effects. The hospital team's conspicuous medical humility was the right approach, fostering good judgment. It allowed the doctors to keep their minds open and to shift course as needed. It also inspired confidence that, despite their expertise, they were not so cocksure that they declined to reinvestigate basic assumptions or even to admit ignorance.

As to the various medical mysteries along the way, [redacted], now that she is well again, is able to live with them quite easily, and, as her parents, so can we.

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