

Unanswered Questions

Dr. Lazow didn't think I had much to worry about, and I was eager to agree with her. Externally, life seemed unchanged with the exception of the birth of our second child, Meredith. Doctor appointments were squeezed into my busy litigation day, and I took a black leather briefcase with me when I went. The contents of the briefcase were irrelevant to the appointments, but carrying the case into the corridors of Columbia Hospital made it look like I was on a business-related visit. I sometimes encountered clients, friends, or relatives at the hospital, and I used the briefcase as a prop so no one would know why I was really there.

Dr. Lazow clipped my last two sets of MRI images into the white-light display case. She silently glanced from image to image, while I closely inspected the different slices of my brain. Even if I searched the scans for hours, I would miss any significant change between the images, but I needed to see them for myself. It was no different than if my car had broken down, compelling me to open the hood and look at the engine, although I would be totally unable to identify the broken part.

The unfamiliar images from inside my head were only pictures, and didn't allow me to come to grips with the damage being inflicted by MS. The white lesions were scattered and slight in their appearance, compared to the overall size of my brain, but there was little solace in viewing their size, because they shouldn't be there at all.

"Is it possible to tell from the MRI images whether I'll become disabled?" I asked Dr. Lazow.

She glanced silently at the images of my second MRI, and then delivered her conclusions with a deadpan demeanor: "Your kind of MS is the type that shows little progression. It will plateau with few exac-

erbatations and no real disability. It will not become much different than it is now.”

I heard the words “no real disability,” which, to me, meant no wheelchair, no walker, and no cane. Maybe the years of obsessive running, physical training, and speedskating had paid off. Dr. Lazow seemed satisfied that the progressing numbness in my fingers and facial muscles had been halted by the massive rounds of prescribed steroids.

If my left hand couldn’t move fast enough to type my legal briefs, then I would dictate them. No one would notice the difference, and my MS would remain under control and invisible. I was physically functional enough for Dr. Lazow, but she still had not offered any insight into my thinking difficulties.

“It sounds like part of your physical fatigue,” she said, during an appointment. “When your body is having trouble with MS, perhaps your mind may also be tired and need a break.”

She wanted to discuss drugs. “Medication might slow down progression of the disease.” This made no sense to me, especially since she had already said that my disease was not progressing. It was starting to become clear to me that Dr. Lazow didn’t understand my condition at all. Why endure the possible side effects of drugs when I may not need them? What would be the point? I decided that intravenous medication was for really sick people, not me. Sometimes denial means hearing only what you want to hear.

Dr. Lazow’s “treatment” was limited to scheduling appointments several months apart. She continued to test my physical balance, coordination, and vision, but we never reviewed my mental clarity. My strained thinking was outside of her standard neurological tests for MS levels of impairment. In retrospect, I realize I should have demanded better answers, but I trusted my doctor.

Consult with a doctor you trust, but also get a second opinion if you are not satisfied with your care.

Dr. Lazow missed the signals that should have alerted her to my MS cognitive disability. While the general literature for MS patients lacked specific discussion regarding these types of symptoms, Dr. Lazow should have taken them more seriously. My care had been incomplete.

I continued to press her for answers. “It’s impossible to focus at work and get through a day without being overwhelmed. All I can do

is close the door and put my head down. Sometimes it helps, most often it doesn't."

"Mr. Gingold," said Dr. Lazow. She paused while flipping through my file, as if trying to remember my medical history. "Maybe you should think about retiring and going on Social Security."

"What!" I screamed. "Quit my job?"

"With what you're facing, it might be wise to explore your options."

My shock at the suggestion of leaving the practice of law was exceeded only by the bruise to my ego.

InsideMS, the quarterly national publication of the MS Society was sitting on the corner of her desk. The same issue had arrived in my mail two days earlier. *Dr. Lazow is a neurologist, and she is supposed to know more than a monthly summary in a magazine*, I thought. But none of the magazines I'd read said anything about problems with focusing at work, remembering details, or getting mentally jammed-up. I was angry, very angry with Dr. Lazow. How had she arrived at the conclusion that I needed to retire?

"It is difficult to know what the MS is doing," said Dr. Lazow, "but we should probably get a different look at how it is affecting you. There are additional tests to measure changes."

Now I was totally confused. None of her conclusions made sense. Appointment after appointment, Dr. Lazow had listened to my complaints, but didn't take them seriously or relate them to MS. Compared to her patients in wheelchairs, my thinking symptoms must have appeared to be minor, but they were powerful, and had the potential to be just as disabling as the physical difficulties of MS. It had been so easy to accept her misinformed diagnosis.

I decided to follow-up on Dr. Lazow's suggestion and go to the MS Neurology Clinic at Froedtert Memorial Lutheran Hospital for neuropsychological testing.

Eleven patients sat in the neurology clinic's waiting room. They were solemn, glancing back and forth from each other to the floor or a magazine. Even the conversation between spouses was, at best, a whisper. This cloistered area behind a partial wall cast a serious tenor, set apart from the hospital bustle of white labcoats and gurneys.

The sound of doctors being paged over the hospital intercom mingled with the nervous clicking sounds of wheelchair brakes, walkers, and canes tapping against chair legs. As I swaggered through the wait-

ing room, my path was blocked from the reception desk by a wheelchair sitting in the aisle. The waiting room was packed by patients' mobility assistance devices. My suit and briefcase set me apart from the casual dress of the other patients, and gave me the appearance of "working." I walked around the obstructing chair and brushed the dust mark left by its wheel off of my black pin-striped pant-leg.

"I'm here to see Dr. Matthais," I said to the receptionist. She held up one finger and answered the phone, which didn't stop ringing even while she was talking on it. Her other hand rested on a keyboard, but she nodded her head that she had heard me. Despite trying to balance so many immediate demands, her forehead and eyes remained soft. She had the compassionate face of a caregiver, and her patience was calming. "Are you a drug-rep?" she said, glancing at my briefcase.

"No," I answered, thinking that I was dressed more like an undertaker. "I have a nine o'clock meeting with the doctor."

Josie Matthais, the neuropsychologist, greeted me in the waiting room. She was younger than I, and appeared casual and confident. She directed me to her office, where she sat down behind her desk and adjusted her shoulders, as if to match my stiff-backed attorney posture. I pulled two of her office chairs together. One for myself and one for the briefcase.

"Your situation presents a number of MS-related possibilities," said Dr. Matthais. "I would like to conduct a battery of tests to help us narrow this down. Since it's early in the day, we can probably accomplish everything today and get you out of here later this afternoon. If you get hungry, you can grab lunch in the cafeteria down the hall."

Neuropsychological testing can be used to identify the cognitive symptoms of MS.

She obviously didn't notice that I was wearing a suit, holding a pen, and taking notes on a legal pad. My calendar was booked weeks in advance. "You want me to clear my whole day?"

"If we get started soon, you may be out by four o'clock. It will save you an additional trip to the clinic if we don't have to do the testing on two separate visits," she said.

I considered the alternatives, and decided it was probably best to face the potentially significant testing, rather than postpone it and then wait and wonder. "Do you mean we can finish the testing today? I can make some calls and rearrange my schedule."

In the end, the tests measured more than correct or incorrect answers. Actually, there probably were no right or wrong answers. One test, in particular, seemed to be designed to measure only one thing: whether I would get ticked-off enough to walk out in the middle of the test. Some of the questions vaporized in my mind before I could find answers. The end feeling of the daylong testing was not good. The verdict from Dr. Matthais would be ready within a few days.

“Your test results are classic for MS cognitive problems,” said Dr. Matthais.

“I know I have MS. What do you mean *cognitive* problems?” I had been anticipating a cane or walker at some point in the future, but I had never heard the word “cognitive” connected to MS. “Classic” meant old cars and *Coca-Cola*, didn’t it?

“Although your intellectual levels tested out at the high to superior range,” she continued, “your mental processing has been slowed, as shown by the lost courtroom incident. In one particular test, it was practically a processing shutdown.” The crisp clarity of Dr. Matthais’s conclusion collided with my expectations, and I double-checked the door, hoping to see that she was talking to someone else who had entered the room. Perhaps sensing my opposition to her conclusion, she adjusted herself in her chair and tucked her straight dark hair behind her ears.

The phrase “cognitive problems” hung in the air between us, unspeakable and impossible to assimilate. My mental stumbling had been summarized with those two words. “The Oklahoma City bombing prosecutor has MS, and he handled the trial from a wheelchair,” I said. “I doubt his brain was slowed.”

About half of all MS patients are affected by cognitive problems, many of them left undiagnosed.

“That may not be his type of MS,” said Dr. Matthais, “but about half of MS patients are affected by similar cognitive problems. Many physicians don’t understand the connection, and their patients remain undiagnosed.” My face clenched, as if facing the blunt press of a wind tunnel. “It’s not easy to identify cognitive problems in MS,” Dr. Matthais continued, softening her approach. “People are hesitant to mention that they are having thinking problems, especially when the difficulty comes and goes. But in your situation, it is clearly interfering with your executive functions and decision-making.”

For months I had been silently wrestling with my diminished concentration and reduced work production, and now Dr. Matthais's matter-of-fact explanation revealed the truth of my nightmarish existence. She said what I had not been able to imagine or allow myself to believe. My worst fears had been brought out into the open. Unknown by me from the start, multiple sclerosis could also mean *thinking fatigue*, and it was as disabling as the physical symptoms of MS.

"We should schedule another appointment to discuss the available medication," said Dr. Matthais. "Your record shows that you're not on any of the current treatments."

"It didn't seem necessary," I said. "What's available isn't good enough. Even the manufacturers of the drugs don't seem too confident about the effectiveness of their products." Dr. Matthais tucked another strand of hair behind her ear, sat back in her chair, and took a deep breath.

"We're going to need to work on this," she said, slightly angling her head and smiling. After scheduling a follow-up appointment to discuss medical treatment, she offered to give me a copy of the thick report so that I could review it at home, in detail. I stuffed the test results and detailed diagnosis under a deposition transcript in my briefcase.

But then, after I left her office, I felt I had to read it immediately, so I sat down in an outer lobby chair and began to review it. The background discussion in the report was familiar, but the analysis and conclusion were as unfamiliar to me as correlating the space shuttle's re-entry specifications to my understanding of how to fill up the gas tank in my car.

I left the hospital and headed for my car in the parking lot. It was gone! Peering up and down the aisle of cars, I felt foolish, and wearing a suit and carrying a briefcase didn't help. Scanning the parking levels above and below, nothing was familiar. The memory of parking my car and its location was completely gone from my head. Only by pacing up and down the aisles, while clicking my remote car key, did I finally trigger the familiar beeping of the vehicle. The point was well received—it's time to stop denying my situation. My life wasn't over, but it definitely was changing.



"Dr. Matthais also told me to consider a different career, one without stress," I told Terri.

There, it's out in the open, but it sounds so drastic, I thought.

“Didn’t Dr. Lazow suggest the same sort of thing?” said Terri.

“Yes, but she never explained why. But now, given Dr. Matthais’s test results, it probably wouldn’t hurt to get a copy of my firm’s disability insurance policy to review. I might need it.”

How could I keep working when I might blank out again in court or in the middle of mediation or negotiating on the phone? I began to contemplate the potential repercussions. I envisioned the unthinkable, perhaps similar to a surgeon who suddenly loses the use of a hand, or an airline pilot who enters a cockpit unable to focus on the control panel. If I stopped practicing law now, it would be more on my terms, and not because I was reeling from a catastrophic and irreversible litigation mistake. At least it wasn’t Alzheimer’s disease—Dr. Matthais explained that memories and level of intelligence are not diminished by the cognitive challenges of MS.

How would I explain retirement at age forty-one to my staff, clients, friends, and family? Only my law partners and Terri knew I had MS. She would understand and support the decision, especially if it might slow the progression of my MS, but how do I tell our girls that Daddy is home to stay? I was standing on the precipice between the pending disaster of where I was and the unknown place I was headed towards.

After three university degrees and twelve years of practicing law, how could I just walk away from it all? It was like experiencing a train collision in slow motion, and there was nothing I could do to stop the oncoming devastation. I needed time to think it through.

Perspectives

- ◆ First, obtain referrals to MS-trained medical professionals.
- ◆ When you consult with your neurologist, bring with you a list of questions regarding your symptoms, potential medications, and therapies, as well as a pen and pad of paper to write down the doctor’s answers for later reference. Offer the doctor the opportunity to make a copy of your written questions and concerns so that they can be included in your medical records.
- ◆ If possible, bring a support person with you to your appointments in order to ensure that all of your questions get asked

and are fully answered. Respectfully demand to be heard and thoroughly examined.

- ◆ Ask the doctor about his experience in treating MS patients with cognitive symptoms.
- ◆ Does the neurological exam discuss both cognitive and physical symptoms? If yes, what are the benchmarks that will be noted? If cognitive symptoms are not included in the exam, ask why.
- ◆ Ask to see your latest MRI and request an explanation of the images as compared to prior images.
- ◆ Ask about the location and size of any lesions or brain atrophy (shrinkage), and how they might relate to your cognitive and physical symptoms.
- ◆ Request an explanation of treatment options, their different benefits, and possible side effects.
- ◆ If the answers to your questions do not make sense or inadequately address your concerns, consider obtaining a second opinion, preferably from an MS-informed neurologist who is recommended by the MS Society.
- ◆ Follow the advice of your doctors and other therapists.