

Introduction

Four days after giving birth, amped up on a combination of hormones and anxiety, I gathered together what was left of my stomach muscles and wrenched myself out of bed. Throwing on a bathrobe, I dragged myself to the neonatal intensive-care unit.

I'd been there before. Shir was our third daughter who had been in the NICU, and even at six-thirty in the morning, even in my postpartum fog, I knew the way through the winding corridors and up the elevator. From the looks of the men in the hallway, I probably had a breast or two hanging out of my robe, but I didn't care. That's how oblivious new mothers are to anything except their newborns. This holds especially true when that newborn is in intensive care, attached to IVs loaded with three antibiotics, two antiviral medications, and a monster dose of barbiturates.

When Shir was two days old, as I held her in my arms, she had a series of seizures that turned part of her face blue. The nurse whisked her upstairs from the maternity ward to the NICU, where neonatologists immediately put her on barbiturates, a standard treatment for seizures. Ever since, she'd been in a barbiturate-induced deep, deep sleep. She looked as if she were in a coma. For the next day and a half, we waited for a team of neurologists, cardiologists, hematologists, and infectious-disease experts to figure out the cause of her seizures. They feared it could be an infection, and so along with daily blood tests and urine tests she'd had a spinal tap

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every day, where doctors stuck a needle into her tiny spinal column to retrieve fluid. Not only is this procedure painful for the baby, it carries with it risks, such as infection, where the needle is inserted.

Finally, the night before my early-morning trip to the NICU, my husband and I received good news. The doctors had determined that the seizures were a fluke and weren't likely to happen again. They told us they would immediately stop the daily spinal taps, take her completely off the antibiotics and antivirals, and cut back on the massive doses of barbiturates that had made Shir so sleepy. In the morning we'd see a different baby, the doctors promised us, one who didn't have so many needles and was much more awake.

Relieved, my husband went home at midnight to be with our two older girls. On my early-morning jaunt to the NICU, I was filled with the hope of seeing my baby awake for the first time in two days.

That's not what I found.

When I arrived at the NICU that morning, Shir was the same rag doll I'd seen the night before; they hadn't decreased the barbiturates at all, and they hadn't taken her off the other medications. I asked the nurse on duty what was going on. Surely she'd received the doctors' orders the night before to stop the drugs and the spinal taps?

"There were no orders last night," she told me, checking the chart. "Everything's the same. They just gave her a spinal tap an hour ago."

What? They were supposed to stop the spinal taps immediately—our doctor had told us that for sure.

There was more. "That spinal tap they just gave her didn't work," the nurse told me. "They got the needle into her spine, and they tried but couldn't get any fluid out because she's dehydrated. They'll try again in an hour."

I couldn't believe what I was hearing. Not only had my baby had one unnecessary spinal tap; she was about to have another. I had to stop them.

“Call the doctor,” I urged. “He’ll tell you: she’s not supposed to have any more spinal taps.”

But the nurse refused. She repeated that Shir would have another spinal tap in an hour. No matter how much I argued, she was adamant.

Nothing had prepared me for this moment: the moment I would have to protect my daughter against a system bent on doing the wrong thing. Not my public-health degree, not my twelve years as a medical journalist at CNN, nothing. Every day I went on TV to explain medical news to the world. But even with that I couldn’t stop this unnecessary, painful procedure from being performed unnecessarily—for the second time—on my tiny baby.

I decided that this wasn’t going to happen. Not on my watch. I planted my sobbing self in a chair, blocking access to Shir’s Isolette. When the doctor arrived to do the spinal tap, I would cut him off at the pass, reminding him that his colleagues had discontinued the spinal taps the night before.

“Oh no, you can’t stay,” the nurse came to tell me. “No visitors between seven and eight, when we change shifts,” she said, pointing to a sign on the wall. “Come back at eight. They’ll have done the spinal by then and you can discuss the results with the doctor.”

She ushered me out of the NICU. Sobbing hard now, I felt that I had failed my daughter. No matter how much I begged the nurse, there seemed to be no way to prevent my baby from having a needle stuck into her spine for no reason whatsoever, and for the second time.

Back in my room, I cried so hysterically that I couldn’t speak. Nurse after nurse came in to find out what was wrong, but I couldn’t get even a syllable out. Finally, a nurse named Sarah managed to calm me down enough so that I could tell her what had happened.

“That’s *bullshit!*” she said. “No way. I’m going right up there.”

To this day, I have no idea what Sarah said, but within minutes I

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received a call from one of the neonatologists saying not to worry, there would be no more spinal taps, and they would start weaning Shir off the IV drugs. Finally, I had managed to protect my daughter. Through my tears, I had been an empowered patient.

When you go for your annual physical, your doctor will tell you to eat right and exercise, get tests like a mammogram or a colonoscopy, and take certain medications and vitamins to keep yourself healthy. That's great, but there are several important—vital, really—things your doctor doesn't tell you. He won't tell you, for example, that doctors often fail to communicate, with sometimes disastrous results, as I learned in the hospital with Shir. When your doctor admits you to the hospital, he won't tell you how truly dangerous a place a hospital really is. Some 99,000 Americans die each year from infections they acquire in the hospital, and as many as another 98,000 die from medical mistakes in the hospital. Taken together, these hospital dangers kill more people than breast cancer, prostate cancer, car accidents, AIDS, and diabetes *combined*.

Your doctor won't alert you to these dangers, but I will. And there's more. You don't have to be in the hospital to fall victim to the shortcomings of our health-care system; you just have to go to see the doctor. Studies tell us that when you go to the doctor with a health problem his diagnosis will be wrong as many as one out of every four times. If you have a lump and the doctor does a biopsy and sends the specimen to a lab to see if it's cancer, more than one time out of ten the pathologist in the lab will make the wrong call. When the test results come back to your doctor's office, there's a good chance the doctor will never call and give you the results—even when the results are bad news and you need treatment fast.

I'm sure that at your next appointment your doctor won't tell you this: physicians play favorites. Women are less likely than men to get the right treatment for a heart attack and many other medical ailments. African-Americans are less likely to get expensive lifesav-

ing treatments even when they have the same medical insurance as white people. Studies have shown that doctors are less likely to spend time with overweight patients. Here's something else your doctor won't tell you about himself: he almost surely has relationships with pharmaceutical companies that influence the choice of drugs he prescribes for you.

Since your doctor won't tell you these things, I will. I'll also tell you what to do about them. I'll tell you how to keep a hospital from killing you, and what steps you need to take to ensure that you get the right diagnosis. And did you know that if you've been waiting in the ER for a long time you can pick up a house phone and ask for the administrator on call? Or that if the price tag for your prescription drug is through the roof your pharmacist can ask your physician to suggest a less expensive drug that will work just as well? Did you know that using certain key words in a letter to your health-insurance company will make it much more likely to pay for an expensive procedure?

Along the way, I'll introduce you to my patient heroes, people who knew more than their doctors did and bucked the system in order to get the care they needed. There's Suzanne, who practically threw herself on the hospital bed when a nurse refused to give her daughter an anesthetic before a painful procedure. There's Albert, who had to step in and stop a nurse from giving his wife a double dose of a medication. There's Jessica, a high school senior, who diagnosed her own Crohn's disease in her science class. There's my sister, Julia, who had to play detective to find a fertility treatment when her doctor refused to lay out all her options. Then there's the actor Dennis Quaid, who became a patient-safety activist after his newborn twin babies received an enormous drug overdose in the hospital that nearly killed them.

I'm writing this book so that you, too, won't have to suffer. Never in the history of modern American health care has there been such an urgent and dramatic need to advocate for yourself and

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the people you love at the doctor's office and in the hospital. But here's the good news: you can do it. You're in control. Just as Suze Orman taught so many of us to take control of our finances, I can teach you how to do the same for your medical care. You *do* have the power to get the best medical care for you and the people you love. In this book, I'll answer these questions for you:

- How do I make sure a hospital doesn't kill me with a medication error or infection?
- How do I know if a doctor has misdiagnosed my condition?
- How do I make sure I have the best doctor?
- How do I get the most out of the short time I have with my doctor?

I want to be clear: I'm not one of those people who believes health care in the United States is a complete disaster. Despite what Michael Moore says, the United States has some of the best care in the world, and my family and I have been grateful recipients of it on many occasions. But getting that excellent care takes know-how, and I want to share with you what I've learned through my reporting and my personal experiences with doctors. In my book, you'll learn the health-care mistakes that are most likely to kill you, and what you can do to keep from becoming a victim.

Remember, doctors are smart, but they don't know everything. You have to take charge.

This isn't a book about complaining. I'll tell you what your doctor doesn't so you can get the best medical care possible. Your life, or the life of someone you love, may depend on it.