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The Perfect Day

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My alarm rang at 5:30 on a chilly winter morning in Chicago. It was dark outside. I rolled out of bed, tiptoed down the too narrow stairway of our home, and began the ritual of making our morning coffee. My yoga class would begin soon, but I wanted my wife, Marla, to enjoy a fresh cup of coffee when she awoke.

Going to a hundred-degree yoga class might not sound like heaven to most people, but it is to me, especially when it's freezing cold outside. Maybe it's because of how different it is from my professional life. As a doctor, anything can happen. And I knew I had a busy day in front of me. My yoga class, on the other hand, is predictable: always the same 26 poses in exactly the same order.

After gathering up my yoga mat, a fresh towel, and a bottle of water, I hopped on my bicycle and pedalled furiously. I arrived at Om on the Range just in time for my 6 a.m. silent yoga class.

I rolled my mat onto the warm wooden floor. The room was softly lit, peaceful, and completely silent, except for the sound of deep breathing dur-

ing our morning meditation and the intermittent whirring of the overhead heater.

I was glad Richard, a pudgy middle-aged man, was there. Richard and I were equally inflexible, so I felt like less of a failure compared to the more limber female yoginis.

Although I can't always move my body into the "full expression" of each posture, I've been taught to measure success in yoga as breathing, paying attention to my body, and staying in the room, even if things get a bit uncomfortable. Not a bad philosophy for life.

The class started and ended with quiet breathing, lying flaccid on our mats in Savasana, the corpse pose.

I left the class refreshed, centred, and powerful. I felt that no matter what else happened that day, I could handle it in a peaceful, calm way.

I showered, ate breakfast, and considered the best way to travel to work. Most winter days, I drive to the hospital. But the sun shone intensely on this January day, melting the dusting of snow that had fallen. I decided to use my preferred mode of transportation, the bicycle. If I left right away, I could still make it in time for the start of the heart catheterization on Maria, one of my patients.

Since childhood, riding my bike was my favourite way to get around. Even in my mid-fifties, I still feel like a kid every time I ride, and I love avoiding traffic jams and gas bills. I donned my helmet and bright orange jacket and set out on the twelve-mile journey from the urban jungle to my suburban children's hospital.

Snow had prevented me from riding my bike for two weeks, and it felt great to be back in the saddle. The intense cloudless winter sky contrasted sharply with the gritty buildings as I headed northwest on Elston Avenue. I rode past the Muslim Community Center, a dimly lit car repair shop, and several car washes with dirty neon signs offering the Early Bird Special. Next came the sprawling Illinois Secretary of State Driver Services Facility, followed by the massive Chicago Transit Authority bus parking lot. Outside the CTA lot, a parked maroon Oldsmobile had a bumper sticker that said, "At Least I Can Still Smoke in My Car!"

I rode past the trees of the Forest Preserve and cemeteries, leafless but strikingly beautiful against the blue winter sky. I breathed in nature and clean suburban air.

I felt like telling someone about my morning. I called my sister in California, and left a message on her voice mail describing the start to my day. After yoga and a winter bike ride, I felt peaceful, confident, and alive. The day was perfect.

I locked my bike outside the hospital and dropped off my backpack and coat in my office. On the way there, my pager went off. I recognized the number. Maria's heart catheterization was about to start in the cath lab.



A few days ago, Maria, a beautiful two-year old girl with long dark hair, tiny gold earrings, and a heart-melting smile had been admitted to the hos-

pital. She had been less energetic than usual and hadn't seemed like herself. An ultrasound showed pulmonary hypertension, high blood pressure in the lungs. This was not good. Even with treatment, patients with pulmonary hypertension often do not survive. If the pressure is too high, the heart can't handle it and fails.

I had met Maria's parents shortly after her birth. She had a major heart problem called *transposition of the great arteries*, and at one week of age she had had open heart surgery, an arterial switch operation. Her chest was opened, she was placed on a heart-lung machine, and her aorta and pulmonary arteries were switched to their correct positions. Maria had done well, despite a rocky start.

Yesterday, I had seen her parents for the first time in almost two years. When I examined Maria, she became agitated, more than most sick children her age. As she cried, her skin turned pale.

Maria's father was thin, with neatly trimmed dark hair. Her mother was short and wore a bright yellow dress. Her hair was tied tightly in a bun. They were grateful their daughter's life had been saved from a lethal condition, but didn't understand why she was sick again. Originally from Mexico, they were trusting, but worried: "Cómo está María?" How's Maria doing? "Cuando puede salir?" When can she go home?

I explained in Spanish the probable diagnosis of pulmonary hypertension, the need to confirm this in the catheterization, and the medicine we would use to treat Maria.

They didn't like the idea of another test.

“Puede salir ahorrita?” Can’t she just go home now?

I explained that Maria could probably go home in a few days, but it was important to figure out what was going on, since pulmonary hypertension is dangerous. Al, the most experienced pediatric cardiologist at our hospital, would do the catheterization to confirm the diagnosis. I would work with him to decide what medicines to give. The parents nodded silently and reluctantly signed the consent form.

I had gained special expertise on this rare condition during my fellowship, when I had worked with one of the leading authorities on childhood pulmonary hypertension and had learned to use special medications to bring down the high pressures.

I arrived in the cath lab changing room. As I put on my scrubs, I could feel my peaceful mood begin to change. It was time to start acting like a doctor.

I donned a leaded vest to protect my body from the radiation. My neck and shoulder muscles tightened slightly, holding up the extra 15 pounds that pressed down on my shoulders.

I entered the cath lab. My partner Al was there, halfway through the procedure that would confirm whether Maria had pulmonary hypertension.

The room was about the same size as my yoga studio, with a focused, quiet energy. Unlike the warm, light brown wooden floors of my class, the floor of the cath lab was grey and spotless, cool, with walls of white ceramic tiles and stainless steel cabinets. All was silent, except for the faint buzz of

overhead fluorescent lights, an intermittent swooshing sound from the ventilator, and the *beep beep beep* of the heart monitor.

Maria, lying on a moveable platform, looked tiny underneath the giant X-ray camera that took pictures of her heart. Unlike yesterday, she was motionless, covered in blue drapes, with only her face and part of her groin visible. To control her airway, an anesthesiologist had placed a breathing tube, given sedation, and was monitoring her vital signs.

A cardiology fellow stood next to the cabinets, watching the procedure. A technician was in the control room recording pressures, another shuttled blood samples from Maria to a machine that measured oxygen levels, and a nurse brought supplies and equipment to the draped table.

With only a sliver of her right groin visible in an opening in the sterile drapes, a small plastic catheter entered Maria's femoral vein. Al, his silver hair mostly covered by his surgical cap, stood next to Maria, guiding the catheter into her heart.

I was glad Al was doing the cath. A seasoned pediatric cardiologist in his early sixties, Al was the best. He'd been doing this procedure for over 30 years.

Although his body was completely covered with a blue sterile cap, gown and booties, Al's eyes sparkled intensely, darting from the patient to the monitor to me, as he concentrated on the task at hand.

I felt nervous, but tried to act calm as I questioned him.

“So, does Maria have pulmonary hypertension?”

“Boy, does she ever! Take a look at those pressure tracings. The pressure in her pulmonary arteries is really high. It’s pretty impressive.”

In the world of medicine, when a doctor says, “It’s impressive,” or “I’m impressed” (which in most situations in life sounds good), it usually means something bad is going on. Looking up at the monitor, I saw the pressure tracings that had so “impressed” Al.

Normally, the blue pulmonary pressures would be located at the bottom of the screen, indicating normal, low pressures. Now, like colorful waves in a stormy sea, the blue waves undulated high on the screen, above the red systemic waves measuring her arm blood pressure. The pulmonary hypertension was even worse than we had suspected. If the medications couldn’t improve things, Maria might not have long to live. The high pressures put a huge strain on her heart. We had to do something.

I tried to regain some of the peace I had felt in my yoga class. Maria depended on me to help guide this procedure. I swallowed, took a deep breath, and offered my advice.

“Let’s go ahead with nitric oxide. Maybe we can bring those pressures down.”

I glanced over at Al. His light blue eyes were staring straight at the monitor. He didn’t waver; he didn’t blink. But I thought I detected a slight quiver in his lower lip. He was nervous too.

The anesthesiologist started nitric oxide, a gas that can help lower pulmonary artery pressure. At first, nothing happened. The pressure remained

high. I knew what we had to do. I used my very best confident and authoritative voice.

“Let’s go to a higher dosage. Up on the nitric!”

Gradually, we increased the dose of nitric oxide. All eyes were focused on the monitor, watching the waves undulate, sometimes a bit higher, sometimes a bit lower. After what seemed like hours, the blue pulmonary artery pressure waves started to drift downward on the screen. My feeling of intense anxiety changed to quiet excitement. The medicine was starting to work.

I could hear gentle sighs of relief from the doctors, nurses and technicians, as we realized there was hope for our patient. Our tension had suddenly dropped like the pulmonary pressures, and everyone was elated. I took a deep “om” breath, and felt a bit of moisture returning to my mouth.

Then, unexpectedly, the red waves, indicating Maria’s systemic arterial pressure, also began to drift lower on the monitor. This could be bad. Nitric oxide mainly relaxes the pulmonary blood circulation, but sometimes can have the same effect on the arteries supplying the body. Although uncommon, I had seen this before during my fellowship. I knew if her struggling heart didn’t get enough blood, it would fail, unable to generate pressure of any kind.

To mask my feeling of helplessness, I matter-of-factly whispered into the ear of the cardiology fellow, “If this kid goes into a full cardiac arrest, she won’t come out of it. Patients with pulmonary hypertension either turn around quickly, or they

don't. If she doesn't improve in the next few minutes, she may be circling the drain."

Maria's blood pressure continued to drop, and her heart rate slowed. My heart started pounding. This was now a full emergency. Crap.

Maria was dying.

Part of me felt an adrenaline rush, ready to dive in. Another part wanted to disappear or escape to the Forest Preserve. Before I could say anything, Al took command.

"Quick, give her some atropine!" he yelled. "Mix up an isoproterenol drip. We've got to get the heart rate up."

After receiving the medicine, Maria's heart rate increased; then, it began to slow again. The *beep beep beep* sounds were spaced further apart. I glanced up at the monitor. The red and blue waves were dangerously low on the monitor.

I looked at the frown on Al's face. His eyes no longer sparkled.

In the midst of this intense situation, my mind turned to Maria's parents. They had no idea any of this was going on, that their daughter might not survive this test.

"I'm going to talk to her family and bring them up to speed," I said to Al.

"Good. We'll keep working on Maria. Should I put in a temporary pacemaker to speed up her heart?"

"You might as well give it a try. I'll be back in a few minutes."

I left the cath lab, hyper-awake, but also in some kind of an out-of-control dream. I wasn't sure what to say.

I walked down the hallway, past neatly piled stacks of scrub suits, past the large sinks for scrubbing in.

I entered the waiting room. An elderly couple huddled in the corner, relatives of another patient. A receptionist sat at a desk, near a pot of coffee that smelled old and partly burnt.

Maria's parents were sitting quietly nearby. They practically jumped up, eager for news of how their daughter was doing.

I wanted to be a strong, wise doctor, but I felt weak, vulnerable, powerless. I wished I could get out of this drama. But I couldn't. I had a job to do.

I swallowed hard and took a breath.

"Maria is very sick. Es muy enferma. We learned a lot of information about her heart. The anatomy looks normal, no narrowing of her arteries or veins. She has high pressures in her lungs and her heart, even worse than we suspected. It's very dangerous. Es peligroso. We gave her some medicine, and the pressure improved."

Maria's parents looked relieved. Her father's hand squeezed his wife's shoulder. They looked briefly at each other, and then back at me, listening politely to my technical jargon. Nodding their heads, they seemed dazed, confused, and not sure what this pressure talk meant.

"Unfortunately, then she got worse. Her heart slowed down and the blood pressure in her arm came down. Right now, the other doctor is putting in a pacemaker."

I studied the parents' faces. They no longer seemed confused. Their eyes had widened. They were shocked and terrified. Exactly how I felt.

Though I didn't really want to, there was one more thing I had to reveal. Like many times before, my doctor training took over.

"Maria is still very sick. We are doing everything we can to help her. She's so sick, there is a chance she might not live through the test."

There was a brief pause. The mother was now angry. She started to shout, pleading with me to do something.

"No. No. No! That's not supposed to happen. It's just a test. What are you talking about?"

Maria's mother cried and screamed, then moved closer to me and pleaded directly: "She has to live, Maria has to live. Don't take my baby away. Don't let her die!"

I could hear myself say some of the doctor platitudes I had learned: "I promise you we are doing everything humanly possible, but she is very, very sick."

Maria's mother and father held each other in a desperate embrace. I looked around the room. The receptionist was reading a book, pretending not to notice what was going on. The other people had left the room.

The peacefulness of my early morning seemed far away. I felt like crying. I felt like screaming. I felt like hopping on my bike and riding home right then.

But I had to act strong. I had to act like things might turn out okay. Like I knew what I was

doing. I was overwhelmed and I didn't know how I would handle it if Maria actually died.

"I'm going back to the cath lab. We are giving her the very strongest medicines we have. I think she can make it. I'll be back in a few minutes to let you know how she's doing." My doctor training kept the outside part of me going. Inside, I wasn't doing so well.

I turned, left the waiting room, and retraced my steps back to the procedure. The overhead fluorescent lights seemed intense, reflecting off the shiny grey floor. I dreaded what I might find in the cath lab.

I took a deep breath, and pushed the door open.

Maria was now in a full cardiac arrest. Al had called a code. He barked out the orders. Nancy, the charge nurse, recorded everything on her clipboard, anesthesiologists administered the meds, in a futile attempt to jump-start Maria's heart. I thought of my prophecy to the cardiology fellow. By now it was clear that no matter what anyone did, she wouldn't make it. Maria's life would end in the cath lab.

Al was the conductor of a symphony of medical personnel, guiding chest compressions, epinephrine, isoproterenol, temporary pacemaker, and shocks from a defibrillator.

I stood silently, observing the frantic scene. It was intense, close, but at the same time distant, far away. I wished it was someone else's patient, someone else's nightmare. But this was my patient. And this was no dream.

Nothing brought her back. The code ended. It was over. Maria was officially dead. The room was quiet. Just the buzzing of the fluorescent lights. And my head.

As a doctor, I felt like a failure. I wanted to crawl onto the floor in a fetal position and disappear. I couldn't do that, so I just stood there and tried to act professional.

All of us were in shock. This wasn't supposed to happen. Even though congenital heart disease is one of the top reasons for death in children, two-year-olds shouldn't die. We were all physically and mentally exhausted.

But our job was not yet finished. We had to tell Maria's parents.

We called for a priest, and then Al, the charge nurse, Nancy, and I went to the waiting area, now cleared of the other families, to talk to her parents.

I recognized the priest, who had visited the bedside of a number of my critically ill patients in the past. Tall, thin, with a wisp of grey hair and a light blue clerical collar, he had a quiet, calm demeanor. I was glad he was there. And not just for the family's sake.

As we walked into the darkened, quiet room, the mood was somber. The silence was deafening.

Al's soft voice pierced the silence.

"The baby died."

After a brief pause, the mother exploded.

"No. No. No. No. Noooooo! Maria can't die, she's too young. No, no, NO!"

Her eyes were wide open, dark, angry, intense. She turned to Al and screamed, in full throttle voice, “YOU KILLED MY BABY!”

She turned to me.

“And *you* killed my baby, too. You *both* killed my baby. *Why* did you kill my baby?”

I took in a deep breath through my nose and exhaled slowly.



In the past, when I had lost patients, I had made it through feeling allied with the parents, like we all had done our best to help the child live. The parents weren't alone, and neither was I. We got through it together, a tragic, shared experience.

That's not how Maria's parents felt. The doctors they had trusted to help their daughter had instead failed miserably. It had to be someone's fault. They blamed Al and they blamed me.

Worst of all, they felt alone. Exactly how we felt.

After the final “You killed my baby,” the room became silent. All I could hear was the quiet, occasionally deep breaths of Maria's mother and father. All I could feel was the pounding of my heart.

I looked at her father. He stared off to the side, stone-faced, silent. His wife's face was full of intense sadness, cheeks moist; her spirit seemed drained.

Her mother began speaking in a slow, deliberate voice.

“I'm going to sue you for killing my baby—and you, too! I'm going to sue you both. *Why* did you kill my baby? *Por qué?*”

I remained frozen. I like to think of myself as a healer, not a killer.

My mind was racing. I felt sorry for Maria, sorry for her parents. I felt sorry for Al. I alternated between feeling guilty and sorry for myself.

How do I explain the unexplainable? How to comfort the inconsolable? How can I find words for something that leaves me speechless?

I understood the shock, the anger, and the need to blame someone for this tragedy. I didn't like being told it was my fault. I already blame myself when things go wrong, and now I had supporting arguments from angry parents. I wanted to fall apart, but I couldn't, at least not now.

While the family talked, we stood silently, nodding our heads, taking deep breaths. Occasionally, Al said, "I am so sorry." I remember saying, "Yes, you are right, this is really awful."

Finally, in a quiet, gentle voice, the priest spoke.

"The doctors feel sad, too. Doctors don't want children to die. Doctors want to help. It's really, really sad that Maria died. I'm so sad. It's very hard to understand."

No one said a word. Used tissues piled up on the floor. The mother's tears started to dry. The father stared away from the group, refusing to interact with anyone.

It was our turn to speak. Al went first. The father turned his head slightly toward Al.

"Even though Maria didn't seem that sick, inside she was very sick. The pressure in her heart was sort of like an iceberg. Even though the part you can see doesn't look too bad, there's a

deeper, submerged part of the problem that's dangerous."

The parents tried to take in the analogy. They remained angry.

It was my turn. There was one more part of this miserable journey I had been taught to include, in hopes of learning from one child's death, in the hope that perhaps a future patient might benefit.

"Because she died suddenly, and we don't completely understand why, I would recommend an autopsy be performed. We need your permission, your signature that it is okay to do the autopsy." It was hard to believe Maria's heart was beating strong less than an hour ago.

Without hesitation, the mother returned to her agitated state.

"No, no, no. You have done enough to my baby. I am not going to let you touch her. Stay away from my baby."

I tried one last time. "Remember your question of why this happened, why Maria died. We are pretty sure the cause was pulmonary hypertension, since it's such a dangerous condition. This is our only chance to find out if there might have been something we didn't know about, that might explain her death. It would be helpful for us, and helpful for you, as we all try to figure out what happened."

They did not sign the consent.

"Contact us in a few weeks, so we can sit down and discuss the whole case and talk about what happened. This is so awful, really tough, but it can help to talk about it. Here is my card, please give me a call."

The parents had completely withdrawn, and would not acknowledge us in any way. I didn't blame them. Finally, Al and I said goodbye to Maria's parents. They said nothing. I walked out of the room, still in a state of shock. The priest stayed.



I glanced at my watch. It was 3:30. I had spent five hours struggling to care for Maria, dealing with her death and her parents. The time had passed quickly, but it also felt like I had been in this hell forever.

I asked the nurse what would happen next. Nancy said the family would most likely return to Maria's room on the pediatric floor, accompanied by the priest, where they could hold her lifeless body and try to take in what had happened.

I was on my own to figure out what happened.

First, there was work to be done, despite my foggy brain. I tried to pull myself together and emerge from my dream-like state. I felt like doing nothing. But some patients' parents had been waiting all day to find out what was going on in their child's heart. It was time to give myself a little pep talk.

I can do this. I have done it before. I will have to do it again. Just because you're tired is no reason to quit working. People need you. You can't fall apart now. Just do the minimum, then you can go home.

I made my way to the heart station where a pile of electrocardiograms and heart ultrasounds were waiting to be read. I leafed through the pile

and tried to pick out the urgent ones, following my new favourite rule, “Don’t do today what you can put off until tomorrow.”

After I finished reading the urgent EKGs and cardiac ultrasounds, I looked through my list of patients and new consultations on the cardiology service. Thankfully, most of them were stable, non-urgent, and could wait until tomorrow.

Only one patient couldn’t wait: a newborn baby with a heart murmur, whose ultrasound I had just reviewed. Newborn babies with heart problems can get very sick, so I had to talk to the family. Even non-doctors know that when something is wrong with the heart, it can be serious business. This boy had mild pulmonary stenosis, a minor problem that is usually no big deal. I could handle that. I prefer to share good news with families, especially this day.

I entered the mother’s room and did my best to focus on the mother and baby at hand, and not on recent events. Since the baby had only a small problem with his heart, I hoped she would be happy. I summoned my best reassuring doctor voice, and tried to forget that things don’t always work out so well.

“We found out what was causing the heart murmur. There is some narrowing of the pulmonary valve, the valve between the heart and the lungs. It’s not dangerous, no need for medicine or surgery. I expect him to do well.”

The mother burst into tears. Sometimes fear of the unknown can have that effect. But this was a

minor issue, and I reassured the mother her child was going to be okay.

“Really, he’s going to be fine. He can live to be 100, he can play in the Olympics, he can be president. Maybe not all at the same time. I’m much more concerned about him growing up in the land of junk food and video games than this little heart issue. I will check him in a few months, just to make sure.”

Slowly, her anxiety turned to relief. Again, she began to cry, this time tears of joy. I congratulated her on her beautiful new baby, gave her my card, and left the room. Yet, when I left, it was Maria who occupied my exploding brain.

I couldn’t bring myself to return to Maria’s room.

I made my way back to the locker room, changed out of my scrubs, and prepared for my bike ride home. It was already pitch black outside. I fumbled around my backpack, located my headlights, and attached them to my bike.

Before leaving, I checked my phone. There was a text message from my sister: “Enjoy your perfect day.” I paused for a minute. And headed out the door.

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