



WELL | LIVE

Learning to Breathe

Voices

By AMY PATUREL SEPT. 28, 2017



The author's son Jack after surgery. Courtesy of Amy Paturel

When my third child was born, I felt extraordinary joy watching him turn from blue to pink in my arms — me holding my breath as he took his first. Unlike our twins, who came surgically six weeks early, my youngest son Jack arrived naturally at nearly 41 weeks. He bypassed the breathing treatments, feeding tubes and incubators that marred our other sons' debuts and even nursed within an hour of birth.

I felt his body warm against my chest, his gentle grip around my finger, and an overwhelming sense that this baby was restitution for our twins' traumatic infancy.

Then, shortly before his first birthday, I called 911 because he was choking on a pretzel. A few weeks later, a virus plugged Jack's airway with mucus and his breathing became so labored, I thought we might lose him.

After the virus cleared, Dr. Seth Pransky at Rady Children's Hospital in San Diego threaded a scope down my baby's throat — and dashed my hopes that Jack's truck-motor breathing sounds were nothing to worry about.

"Jack needs immediate surgery," he said.

Dr. Pransky explained that Jack, then 14 months old, had an extra branch stemming from his heart. Called a double aortic arch, the branch forms a ring around the airway, acting almost like a vise.

I tried to grasp our new reality: Jack was flawed. Maybe it was the copious quantities of NyQuil I had chugged to drown a cold around the time we conceived. Or the wine I drank before the cells that were Jack attached to my uterus. Or the stress of ditching our twins' diapers, binkies and thumb-sucking in the months before Jack arrived. Though the doctors dismissed those theories, I was convinced that Jack's structural defect was my fault — and he was blissfully unaware I had failed him.

That night, I marveled at his easygoing charm. Nurses entertained him by tapping on the glass door of his hospital room and blowing a pinwheel. He giggled and tapped back.

When doctors transported Jack to the operating room the next morning, they blew bubbles to distract him. The perfect iridescent spheres burst in my face while my husband, Brandon, and I clung to each other; Brandon with tears in his eyes, me sobbing once Jack was out of sight.

Four hours later, we learned Jack made it through surgery. At first we were relieved. But the soul-crushing news came overnight when Jack's chest tube started pumping out fluid. He had a condition known as a chylothorax, which can be caused by injury to the lymphatic system during surgery.

We had two choices to sop up the fluid: Put Jack through another operation or restrict food and water, giving him only minimal intravenous nutrition, until his system dried out. We chose the latter.

I watched in horror as my child transformed into a caged animal, his hospital bed outfitted with jail-cell-like rails that extended almost to the ceiling. Though I tried to hide any sign of food or water, Jack nearly jumped out of his bed from frustration, yelling, "wa-wa!"

Instead of water, nurses served up pharmaceutical cocktails: Diuretics to dry up the fluid, morphine for pain, Tylenol for fever, steroids to bolster his breath and narcotics to sedate him into submission.

Every drug, drip and medical intervention clocked me in the gut.

"This has to stop," I told the nurse at 2 a.m., after Jack had spent 78 hours on food and water restriction. "He looks possessed."

"I'm sorry," she said. "Jack has strict orders. You can discuss your concerns with the doctor tomorrow."

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"This is not O.K.," I said, raising my voice. "When you watch your child transform into something out of 'American Horror Story,' you can tell me we'll address it in the morning."

I demanded the physician on call take Jack off the meds and lift his food restrictions. "A second operation to repair the chylothorax would be less traumatic for all of us," I said.

The doctor acquiesced. Jack

gulped down water and neon green Jell-O before curling up beside me in his hospital bed.

Since I couldn't control Jack's outcome by waving a magic wand or wielding surgical tools, I fixated on minutiae and silently bargained with God. Over hospital room dinners (child-size bean and cheese burritos with smuggled-in chardonnay from a gas station minimart), I tallied how many X-rays Jack had, researched how pain meds affect the developing brain and prayed Jack would someday view dime-store bubbles with the same wonder and excitement as other kids.

Over time, Jack healed; a second surgery sealed the leak and he was released. Back home, he endured thrice daily breathing treatments and myriad medications, appointments and tests, all meant to counter the sad reality that after all of the medical hoopla, Jack's trachea was still 80 percent obstructed.

Although the surgery succeeded in dividing the [vascular ring](#) that had been compressing his trachea, Dr. Pransky explained that it would not snap back right away — it would need time to expand.

"How long?" I asked.

"I can't say. It could be two months or two years. We just have to wait and see," he said, trying to sound encouraging.

So, we spent our days on high alert and the choking episodes continued. Over a three-month period, we dialed 911 three times, landed in the emergency room four times, and had to be helicoptered to Children's Hospital twice. Each time Jack was choking.

It felt as if Rady Children's Hospital had a revolving door exclusively for Jack — and with every visit I faced heart-wrenching choices. Get another X-ray and accompanying radiation or risk Jack's system shutting down from excess fluid? Medicate him to help alleviate physical and emotional stress or steer clear of meds because they may have long-term effects?

But during those hospital visits, something shifted. As I pulled Jack through the halls in a little red wagon, we passed families who had all the cards stacked against them. A child born with half a heart, desperate for a transplant; a teenager undergoing his seventh operation to keep pace with a congenital heart condition; and, most devastating, an infant who died in a hospital bed beside her anguished parents.

Their struggles smacked me with a truism I didn't want to face: Our children's lives are not something we can orchestrate. Everything from Jack's ostensibly perfect birth to his elaborate medical odyssey fell outside my control.

Just 18 months after his first operation, the scar across Jack's left rib had faded and his trachea had grown to normal size. Thankfully, bubbles now make him giggle with delight. They serve another purpose, too: Reminding me to celebrate every day with my three kids; to sneak into their rooms at night and watch their bellies rise and fall; to hold them close, but also let them grow.

Now when I hear a siren in the distance, I pray for the family in crisis — and for Jack's continued health. He is here with us, and today he can breathe.

[Amy Paturel](#) is a health and nutrition writer based in Southern California.