

You Should See the Other Guy

Today is Tuesday, July 18th, 2017.

I have no book-related content this time — although as always, I have lots of reading to talk about. Maybe next time.

My wonderful daughter Elanor, also known to her siblings as Ellie Nellie, had open-heart surgery for a VSD (ventricular septal defect, or hole in her heart). This is the most common congenital heart defect. She also had a small ASD (atrial septal defect) as well, which her surgeon also closed. We're told she now has a Gore-Tex™ patch sewn into the middle of her heart. I expect her to have a lifelong love of waterproof boots and jackets. Maybe she'll hike the Appalachian Trail.

Her surgery was the morning of July 10th, and today we brought her back home. She shows every indication of having come through the surgery very well and is recovering nicely. The news is almost all very good. We have some slight concern about a little bit of pulmonary hypertension and maybe some reduced function in her left ventricle, but everything seemed to be moving in the right direction, so she was cleared to come home. She will have a detailed follow-up exam in under a week.

The surgery is quite amazing. On the one hand, it seems miraculous, an incredible mix of technological advancement and medical know-how. On the other hand, it seems horrifying and barbaric. The incision is large and the surgeon cut right through the sternum, which was then wired together. Honestly, it gives me the heebie-jeebies. I'm reminded of Doctor McCoy's reaction to twentieth-century medicine in *Star Trek IV: The Voyage Home*:

My God man, drilling holes in his head is not the answer! The artery must be repaired! Now, put away your butcher's knives and let me save this patient before it's too late!

And in *The City on the Edge of Forever*:

All the pain. They used to hand-cut and sew people like garments. Needles and sutures. Oh, the terrible pain!

Fortunately, as far as we can tell, Ellie Nellie didn't experience a lot of pain. After a terrible night's sleep last Sunday — Grace and I had trouble sleeping the night before they were to cut open our daughter, go figure — we arrived at

the hospital at 6:00 a.m. I thought they would do some prep that might involve putting in IVs, but since they needed to anaesthetize her with gas anyway, they just gave her a quick exam and asked us a few questions, to verify that her stomach was empty. Then the anaesthesiologist put her up on his shoulder and carried her off, and they began by giving her gas.

We then had a long morning of waiting around. A nurse practitioner came by periodically to give us an update. All the news was good, which was reassuring. They set her up in the pediatric intensive care unit, and after a little more waiting we were able to go there and see her. She had a frightening number of tubes and wires — two ports in her groin, a chest tube, a urinary catheter, pacing wires, and at least one IV — as well as a huge bandage and some visible bruising on her chest — but it was immediately apparent that she had come through the surgery quite well. Her color was good. She was initially on intravenous morphine, and so she was quite dopey, and slept most of the time. She didn't open her eyes a whole lot, but when she did, she had this look of confused concern, like she was asking "what the hell happened to me?"

"Don't worry, baby," we told her. "You were in a knife fight. But you won! And you should see the other guy!"

Actually our daughter's surgeon was a woman, but that kind of throws off the phrasing. "You should see the other gal," maybe?

With our baby in the ICU, we got a room in the Corporate McSponsor house right in the building, so we had an extra place to sleep. I got a nap for a while, then Grace got a nap, then I slept in the room while she slept in the fold-out chair in the ICU. Grace can sleep anywhere while I am a very light sleeper, so I generally just can't get any sleep in a hospital room at all. I set my alarm for five hours and then was back in the ICU the next morning.

Ellie Nellie was improving so rapidly that she was moved to a part of the ICU designated for less critical patients, and then by the end of day two, was moved into a regular room. We didn't get the room for a second night, since she was out of the ICU, so I went home to get a mostly normal night's sleep. Grace continued to sleep by Elanor's bedside, and in fact she didn't really leave the hospital, except for a walk in the courtyard, until today, spending eight nights there.

We knew she was doing well when Grace woke up after a nap and found the bed empty. She stuck her head out in the hall and found that the nurses had rolled Ellie Nellie out to the nurse's station and the nurses were gathered around cooing at her. They looked just a bit embarrassed when Grace got there — "oh, sorry," they said, "we wanted to play with her."

Elanor's cardiologist had told us how things would most likely go — that there would probably be a number of minor concerns and "annoying things," but that she would gradually get her tubes and wires out, and with each tube and wire removed, she'd be "closer to the door." This happened surprisingly quickly. On

Thursday she had her chest tube removed — I wasn't there to see it, but it is surprisingly long, going right into the chest, and they pull the incision closed with one little stitch, and then stick on an ordinary adhesive bandage.

Besides all the complications from the surgery itself, the big risk is infection. We washed our hands pretty obsessively around her. They had some special infection protocols, and wiped her down with some sort of disinfectant solution. Hospital infections (“nosocomial” or “iatrogenic” are the technical terms) are no joke these days, with antibiotic-resistant organisms around. But so far she's shown no sign of infection at all.

The “annoying” things included itching — apparently morphine made her face itchy, and she was constantly scratching at her face. She really hated her nasal cannula, which was delivering a little oxygen, so when we could, we'd take it off and give her “blow-by”, a little breeze of oxygen blowing past her face. This seemed to be enough to keep her blood oxygenation reading 91% or greater, although every once in a while it would drop a bit, especially when she was in deep sleep, and they would have to put the cannula back in. After she was taken off morphine, the itching went away. She had to get a little more morphine when her chest tube was removed, so it came back.

Another annoying issue was “extravasation” — when an intravenous fluid leaks into body tissues instead of going into the vein. This happened in her arm, and it blew up like a sausage. I met with her doctors at rounds and expressed my displeasure that this had happened, saying I didn't think she needed this particular round of IV fluids. I did not raise my voice, but told them I was angry about this. It seemed to Grace that the night nurse had put in the IV because Grace wasn't waking her up to nurse her as often as the nurse thought she should, and this triggered bad memories of arguing with night nurses about feedings — after basically every one of our children's births.

One of her doctors explained that there can be a lot of fluid in the tissues that isn't making it into the bloodstream. Elanor had been retaining some fluid and I guess they were concerned that she wasn't urinating enough, although the tests were showing that her kidneys were fine. Since all I really know about medicine, I learned from watching *M.A.S.H.*, I have to admit that I might have been wrong about the IV being unnecessary (although of course if the fluid was all going into her arm and blowing it up, it didn't actually do much to help her urinate). I was unhappy that she had been made uncomfortable by this particular intervention — and especially that it hadn't been caught before there was very noticeable swelling. Fortunately the swelling went down pretty quickly after they removed the IV, and the diuretics kicked in and she started soaking diapers. I also wonder if some of this was just because the catheter was hard on her tiny baby urethra, and her body needed to recover a bit before she felt comfortable peeing properly, and so she was “holding it.” But we couldn't ask her about that.

I took only three days off work — after days off for her birth in January, and

days off for moving, and days off for more packing at the hold house, I had almost no days off left to take. So I went back to work last Thursday and Friday. I got a few things done, although I'd be lying if I said I was really at my best.

We thought we might be allowed to bring Elanor home on Monday, but they wanted to watch her a bit longer. She had developed a little bit of pulmonary hypertension — some fluid around the lungs. That improved pretty quickly. Her left ventricle function seemed to be down a bit, so she's on a medication for that. Her cardiologist told her that it's not uncommon for a heart just recently traumatized by surgery to show some reduction in functioning while it heals.

Speaking of healing, I just have to comment again how amazing it was to watch Ellie Nellie heal. Of course she isn't done, but by day four, I think, she was off all IV pain medication, and was only getting some oral children's acetaminophin. She got her bandage off. She slept a lot, and often quite deeply, and during that deep sleep her body just magically repaired the collateral damage. Amazing. If I had the same procedure, I really don't think I'd recover nearly as fast as she did. Babies are amazing.

You know what else is amazing? The physicians and nursing staff at the PICU and elsewhere in Mott Children's Hospital. They were so great. I really enjoyed chatting with them. It was actually a little frustrating that Ellie Nellie was recuperating so quickly, because as soon as I'd get to know a nurse, we'd be moving on.

You know what's not amazing? Our system of for-profit medical insurance.

While she was in the hospital, we continued to get letters from our insurance provider, copies of letters sent to Elanor's physicians, saying they could not approve the surgery without more documentation to show that it was medical necessary. (Hell no — we just slice open five-month-old babies for fun). We also had letters saying that the surgery was approved, even though Mott was out-of-network, because there was no nearby place to do it that was in-network. Elanor was also approved for a three-day hospital stay.

Three days? That's nuts — that isn't any reasonable standard of care. On day three, she still had a chest tube and was on a number of IV medications. Were we supposed to just toss her in the car seat and go?

I can't imagine that any person of any age would be ready to leave the hospital on day three after open-heart surgery. Then our insurer called Grace to say that Elanor's prescriptions were not covered — although I had put her on our insurance shortly after her birth in January. Apparently that was just a debating tactic. They are arguing whether some of her specific prescriptions are medically necessary. Grace has been patiently doing this dance, and making sure they get whatever documentation they want.

I'm pretty sure it will work out, and her care will be paid for somehow. If her insurer fights it, there is a Michigan program especially for children with congenital heart defects, and it is supposed to cover costs that regular insurance

won't cover. If those two forms of insurance together won't cover most of it, and we're left with a huge bill — well, I earn a good living, but like most Americans these days we don't actually have much in the way of assets. I'm guessing the total cost of her care so far is probably well over a hundred thousand dollars. If we have to pay that, I think we'll be looking at bankruptcy, which wouldn't be the worst thing, as long as we can find a way to keep the house we are living in and a car so I can get to my job. But I think it won't come to that.

If you're the praying type, please pray for my baby girl — that she continues to recover, and has no long-term developmental troubles or issues arising from her heart defect and the surgery. If you're the positive vibrations type, please send those too. I feel very fortunate. I was a little sleep-deprived for a few days, but it really wasn't that bad. We had some great help with child care, and I'm grateful for that. Grace was a trooper. There are many, many very good reasons that I married her, and she really demonstrated those reasons this past week.

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