

Empty Sunrise

March 22, 2015

I sat on the couch in the living room staring at the speckled brick of the fireplace. My stomach turned. What if I woke up one morning and the sun didn't rise. I jiggled my leg in hope of distracting myself. Tension was building in my body. The sun was blazing through the two-story south facing window. Fresh snow reflected rays of bright morning sun; the light bringing the false promise of warmth into the living room. Maybe jiggling my other leg as well, but alternating them, will help me distract me. I could feel a welling up sensation in my chest, my eyes were watering. This is too much to handle, the pain, nausea, and the fact that my son is sick.

His round, soft face is now slack, his eyes sunken in. He's limp in my arms. What fresh hell have I woken into this morning. Please, give me his suffering and his illness, let me take this pain for him. I imagine him dying—What if I wake up one morning and the sun doesn't rise. I don't want to miss you, buddy, I love you so much. I try to force the thought into him, imagining how thinking it will make him better. He looks around the room, his gaze is restless and fitful. I don't want to miss you. My sinuses swell, the tears well in my eyes, there's that familiar burning in my mid-face. I sob. I look at him again and grab his bottle from the side table. The sun makes a prism through the Pedialyte¹ in the bottle. When I lift the bottle up the effect is gone. I can barely see through my tear-filled eyes. I tip the bottle up, holding it with a light grip, just the fingertips, and place it into my son's mouth. His feeding is listless, he doesn't drink fast, doesn't drink much. This isn't the first time this he's gotten sick like this², last time he was hospitalized for a week, he couldn't

¹ An electrolyte-balanced fluid for rehydrating sick children, It works in a near-miraculous way, provided you can actually get your child to drink it — It tastes like tears with grape flavor added.™ Abbott Nutrition.

² He had gotten sick around his 3 month mark, in November.

keep fluids down, he stopped eating, he almost died. My wife walks into the room, her boots click-click on the hardwood floor as she approaches. She's carrying bags, sets them on the floor in front of me. There's a growing pile of stuff to take with us. The look she gives me conveys both fear for our son and pity for me. I can feel the love in her gaze. I look down at Babo's³ face, I see his blue eyes and dry mouth twisted into a tiny grimace. I look at my wife, hold him up and out in front of me; I present him, arms outstretched. She takes him and puts him into the car seat fastening all the straps and buckles around his limp limbs. I stand up, overtaken by a queasy feeling, and approach the mountain of bags.

My eyes are still puffy from crying as we drive to the hospital. I think about how much I love my wife, and this tiny little man, how much it hurts to think about life without him. This morning the sky is a piercing, winter blue with the bright sun working its way up the sky. The condition of the road is not bad, most of the snow is gone, plus it's early in the week and everyone is already at work. We picked a good time in the late morning to head into the hospital. We'll go to the clinic first to see if he can be taken care of outpatient. The whole drive is filled with doubt, fear. I don't want to live without my son, what if I wake up and the sun doesn't rise—I stop myself in mid thought to pay attention to the road. We approach the hospital and the parking lot, its massive size imposing, I feel a deep nagging in my gut, something beyond my nausea.

The waiting room has only a few kids in it. Ratatouille plays in the corner⁴. It keeps stopping on a frame every few seconds, then plays a bit more. I don't think anyone is

³ When my son was two days old I called him Captain Babo—I imagined him as the captain of a very adorable little space ship. I have no idea why, but the name stuck.

⁴ Not too long ago, I talked with the father of a very sick child in this waiting room about Ratatouille, he informed me that it was a Pixar venture and that Pixar was indeed founded by Steve Jobs. It has ostensibly been playing for months on end in here.

watching it. There's an older man standing next to the TV. He's on the phone, he paces, his face carries a deep worn look of sadness. Marra and I talk for a few minutes, try to keep Babo calm. I try not to look too much at him—his skin is pale, his eyes look sunken into his skull, his gaze is vacant and roaming. His appearance reminds me of Tad⁵. I breathe, a solid slow breath, as I exhale, they call us back to see the doctor.

Clinic is not very busy; they pack us into a corner room, with all our bags, sick baby in tow. We clearly aren't optimistic about taking care of this whole ordeal as an outpatient⁶ but they don't seem to mind. The doctor is in a good mood, he's energetic and caring, makes sure we feel heard and understood.

"We want to try to take care of Lytt outpatient, we are going to draw some labs and give him some fluids. If the labs don't look too bad we can just do everything here in the clinic and send him home, OK?" As he talks to us I can't help but notice the dense forest of black hair on the back of his hands.

"We're going to order a few ultrasounds to rule out intussusception and check for renal stones" I wonder if rare orchids grow in that veritable arm-hair forest.

"The blood tests we're ordering are just to see how dehydrated Lytt is and to look at how his kidneys and liver are doing, OK Mom, Dad?"

We agree to the plan. This is standard stuff, but when it's your child nothing is standard, nothing run-of-the-mill.

⁵ Poor Tad was a good friend of mine, he was diagnosed with metastatic melanoma in his early thirties. After several rounds of treatment with no progress made on his cancer they decided to try for quality of life. They did a good job preserving his function and keeping him comfortable as the cancer hollowed out his mind and body, day by day.

⁶ It must seem obvious to the staff when mom has the baby and dad is carrying a packed-full camping backpack, messenger bag, diaper bag, and breastpump bag.

We go to the lab. We wait. We put on some cream to reduce Babo's pain for the lab draws. We wait. We get blood drawn. It takes two agonizing pokes. We wait. We go upstairs for renal, abdominal ultrasounds. We wait—We do a lot of waiting. Marra and I spend too much time on our phones. I check my email compulsively; I'm now checking the same two email accounts every minute despite knowing there's no reason to even have my phone out. I check again, an email, there's a new result on MyChart. I load the website, and log in. There's new labs on Lytt's account. So far, his labs suggest he's just a little dehydrated. This is good news; I was worried. I check the PT/PTT—his clotting times are unmeasurably high. My heart rate increases, my head gets lighter, and my heart drops into the pit of my stomach—It's happening again, what's wrong with my Babo. I thought we fixed this in November. A wave of anxiety flushes over me. I breathe, I stop it before it completely enshrouds me. I look up at my wife, her light blue eyes have a slight tinge of sadness. She's chewing on her lower lip a little. It hits me—I feel the familiar welling up in my chest, the tiny metallic feeling in my nose. I halt a sob as the emotion bubbles to the surface—What if I wake up tomorrow and the sun doesn't rise.

We got a room on the second floor and, after getting situated, had to be moved to the third floor; the second floor is overflow from the NICU and things are apparently really busy. It's a shame, the nurse we have on two is really good, we had her last time we were in the hospital. We moved up to three. Everything in the hospital takes a lot longer than you would think and this was a good example. It took us two hours to get a room on two and then another hour to get a different room on three. Right now, the worst feeling associated

with the hospital is this rootlessness; we're unmoored and wandering, floating from place to place without homes—we're ghosts haunting the hospital.

Once we're situated, we meet with all the teams, GI, Hematology/Oncology, General Pediatrics. They order tests, we talk about what's going on. We tell Babo's story four, maybe five times to all the different teams. Despite the repetition, I never get tired of recounting the whole story, it makes me feel like there's something I can do, like there's a positive contribution I can make. It occurs to me that helplessness is much worse than the feeling of wandering. I am a medical student, and I worked as a paramedic for years, I have experience in medicine, my wife is a pharmacist, my mother a pediatrician. I grew up around medicine, I'm steeped in it. I know how to do a lot of things in medicine too, I've even done a few myself, yet there is simply nothing for me to do—nothing I can do to make him better, figure out what is causing him to be so sick. How must it feel to know even less than I do. Does it make it better to be completely in the unknown? I'm already hooked on the addiction of modern medicine, the incessant knowing. Is it better to know than to not know, even if there's nothing to be done? Knowing is pervasive, it's powerful because it can lift the veil on a condition, unveil a dark spectre you can chase away. Even if there are only a handful of things you can solve through direct medical intervention the ability to know more about the situation has opened pandora's box. It is compelling—knowing has crept into our collective psyche like the Zahir⁷ and will blot out the light of all other possibility.

At night, the third floor is dark, the doors closed, and most of the families are in their rooms. Nurses seem to become invisible in the central hallways at this hour. It's secretly

⁷ The Zahir is an mythological object which, upon viewing, has the power to create an all-encompassing obsession in the viewer—After you have seen the Zahir it becomes an obsession so powerful It pushes out all other perception until there is nothing left but the Zahir itself.

busy, they're in and out of rooms, winding their way across the unit. I can't sleep so I walk the unit—we're on the heme/onc service and I'm certain we are the only family in this section of the unit who doesn't have cancer. My shoes make a squeak that sounds like they are always wet. As I pace the floor the faint echoes of this squeaking trails me, and gives the impression I'm being followed. There's enough background noise throughout the unit that I know the sound won't disturb anyone's sleep. The shape of the unit is convoluted, a central winding hallway with little horseshoe segments herniating from the main line. At the far end is the bone marrow transplant unit. It's sealed off from the main hallway by spotless double glass door airlocks. There's a large sink inside the airlock. It's clean and polished, imposing, almost threatening, but, weirdly inspiring. It makes me realize the capabilities we have in medicine, the lives of all the kids we can save that just a century ago would have been doomed to a tragic death. My son will be one of those kids, if we can save him. I stare at the airlock. My mind returns to Babo, what's wrong with him, what's going on? I can't help but think about him suffering, I can see him squirming and thrashing as the life drains from him. The air around me turns stale and has a must, like rebreathing someone else's air—What if I'm inside that airlock? Each breath becomes more and more labored until the air is evicted of all sustenance, I choke and gasp. I turn from the double doors and head back down the unit. My eyes burn and I blink to no relief. The air is so dry my eyelids lag when I blink, they stick to the surface of my eye and drag. It feels like something stuck in my eye. I know that's unlikely. Since my condition⁸ started I haven't had an eyelash in my eye for almost a year. I round the corner before my son's room and I see another father

⁸ *Alopecia Areata Universalis*: I haven't a hair on my body except my eyebrows, which are only just re-appearing, owing to monthly, extremely painful, steroid injections.

walking the unit. He's tall, has dark hair, and an impressive five-o'clock shadow. We make brief eye contact. We just acknowledge each others' existence. Our exchange conveys a solidarity that comes from knowing your kids are sick, knowing this other person can share the fear, doubt and terror you're going through. Most of all it's knowing this other person is as powerless and helpless as you. He turns to walk down his hall, I turn back towards the marrow transplant unit and the bond we share dissolves.

Every room in the children's hospital has something for parents to sleep on. Sometimes it's a recliner, a pull out chair, or, if you're really lucky, a pull-out sofa. Our room has two sleepers squeezed into it, a pull-out chair and a recliner. My wife has the pull out chair opened, and next to the crib. I sleep in the recliner⁹ crammed into the space between the large window and her chair. I get about seven hours to sleep every night but I never sleep more than 90 minutes in a go. I wake up in the middle of the night a lot and awaken with a jolt, not unlike being shocked. It's a sudden sense of dread, but I don't have any nightmares, no memorable dream content. Instead, I wake up in a complete, bottomless state of terror¹⁰. This broken, listless sleep ensures I am not quite conscious enough to function normally. I'm not tired all day, but I'm never well-rested enough to be completely sane. This makes it challenging to be a supportive husband and a doting father, especially when my son is sick.

I'm pacing around the unit again. It's midday and we're hoping to go home tomorrow. Babo's getting better, he's having fewer, more solid stools, and he's bottle

⁹ If ever you have to sleep on a recliner in the hospital there are some important things worth noting. First these recliners are completely impenetrable with respect to liquids; this makes sense considering the prevalence of vulgar, bodily fluids in a hospital. However this same invulnerability to liquids prevents them being breathable at all and you will rapidly find yourself with an acquired case of the so called 'swamp ass'.

¹⁰ These are presumably night terrors.

feeding again. We're able to keep him hydrated with just bottle-fed breast milk alone. His IV was discontinued early yesterday evening. I'm pacing because I'm waiting for the phlebotomy team to get here to do one last round of labs. The team ordered a bunch of send-out labs for rare immunological disorders yesterday and, Marra and I debated whether we should even have them drawn now, it sounds like its going to be a lot of blood to draw. Babo weighed about 14 pounds when we came into the hospital, that puts his blood volume somewhere around 500 milliliters. There are significant restrictions with respect to drawing blood and the volumes you can take¹¹, and Babo has almost hit his limit. It would be a bad idea to take more than a few milliliters of blood this round. Only the clotting studies are critical to get done today, and that shouldn't take too much blood. We talked about having some of the other labs done today, at least one particular test, because it takes about three or four weeks to get back results and we'll want the results before we meet with the immunologist in a month. I pace the long hallway. It's around lunch time and the unit is in quiet-time mode, the lights are dimmed, doors closed and things are almost silent. I ought to go get some lunch since the team isn't here yet. I return to the room to tell this to Marra.

"I want to go get lunch."

"Sounds good honey." she says.

"The second I leave here the team is going to show up to draw his blood."

"Yeah." She pauses and looks around the room a bit.

"Can you help me clean up in here before you go?" she says.

¹¹ Namely, never take more than 2.5% of blood volume in a given draw. Also, no more than 5% to 10% of total blood volume within a 30 day period - there are disagreements in the literature whether 5% or 10% is the maximum value.

“I have to use the bathroom first.”

“I love you.”

“I love you too.”

I use the bathroom and clean up some of the things around the room before I go. I head towards the unit door. Two young people in short lab coats and scrubs are rolling a little mobile desk towards the horseshoe hallway where Babo’s room is. I knew it, here they come. I stop them and ask if they are here for Lytt. We talk about what labs need to be drawn and what the plan is for drawing them. I let him know Marra and I had been talking about how much total blood could be drawn, the technician who’s going to do the needlestick tells me they will only need six milliliters for all the remaining labs. We decide he can pull all the labs if he can do it without waste, Lytt’s already had so much blood drawn.

He’s going to be a little anemic after this but we will be at home where he’ll be exposed to fewer dangerous infections and, more importantly, we might know what’s making him so sick. I hope we can figure it out and treat it. Maybe if I know what’s going on I can save him from the misery he’s going through. Maybe I can prevent this from ever happening again—I think about him dying, I imagine all our family dressed in dark suits and dresses. We are gathered around a picture of him with his biggest, brightest, smile. I’m at the front of the crowd giving his eulogy, I cry—what if I wake up, the sun doesn’t... I bring myself to attention and take the team into my son’s room. It took the neonatal transport team¹² an hour and a half to draw blood on him the other day, and that was only after the

¹² The neonatal transport team and the helicopter medics are the resident bad-asses of blood draws and generally tricky IV starts at the hospital.

best nurse on the floor tried for an hour and a half. We have all the usual distractions ready, a bottle of breastmilk, the little sugar water stuff they give you to put on the pacifier, the rain drum, everything. The technician puts the tourniquet on, sizes up the vein in the crook of Lytt's right arm. He cleanses it and gets his butterfly needle lined up at a shallow angle. We have Lytt locked down, three people holding his various limbs at bay. He's screaming at the top of his lungs, turning plum colored, inconsolable. The tech sticks him, there's an instant flash of blood in the tubing. He pulls the plunger on the syringe, perfect draw, all six milliliters in one go. It was artwork, master craftsmanship. After, the tech gave us his card and pager number so he could draw all the outpatient labs for Lytt when the time comes. I thank the tech. He and his colleague walk out, taking the valuable blood with them, all the samples in their proper tubes and ready to go to the lab. I go downstairs for lunch and I'm still awestruck about the blood draw when I walk back to the room with hot stir-fry, and pecan pie in hand.

I pile our stuff on a wheelchair so I can take it all to the car myself. It's still freezing outside and I am not excited for the trip between the hospital and our car. Now that Babo is getting discharged I'm ready to get us all home. In the hospital, it's easier to do the tests and procedures that make modern medicine work and that's part of my attraction to medicine. But as a patient, the hospital is an unfamiliar place where you're forced to surrender your will. Living in the hospital with a sick child changes you, it exposes you to your true powerlessness; that lesson is invaluable but it came to me at a price I would never willingly pay. I thought I'd miss the hospital, that I might have some wistful thoughts about this journey but as I push the wheelchair, brimming with our worldly possessions, up

the ramp towards the car I realize I want to get as far from here as possible. The bags seem heavier, I load them one at a time into the car and realize how much stuff we accumulated throughout our time at the hospital. All my nightly trips home to grab this or that, all the gifts people brought us during our stay added up quickly. I slam the back door of the car and admire how well everything fits inside. As I return the wheelchair to the elevator area it dawns on me how far I've come in the last week. I have no idea what's at the bottom of this, what caused my son's blood to stop clotting, but I feel moved, like the hospital reached into me, restructured my character. I've crossed an enormous threshold. The driver's seat is so cold my teeth chatter as I get situated and turn the car on. I stomp on the clutch forcing my muscles to work through the cold and throw the car into gear. I head to the side entrance to pick up my wife and son so we can finally go home.

It's late at night, I awoke abruptly¹³ and I'm out of bed trying to extinguish my fear. Sometimes when I'm up like this, I'll hear my son screaming from the bedroom. I go downstairs to check on him, he's fine, of course he's fine. He's not even awake, maybe he never screamed at all. I remember late nights, seeing him sick, all pale and limp, he looked like someone else's child. I remember my fear, thinking about him dying—what if I wake up and the sun doesn't rise. I walk back upstairs taking methodical steps to ensure the stairs don't creak. I get a glass of water to ease my nerves and help put the terror behind me—Focus on the water, feel it flowing, feel it slide down my throat. I'm standing in the kitchen in front of the heating vent, hot air blowing onto my cold, sweaty feet. It feels good to indulge. A warm glowing sensation spreads from my feet to the center of my chest. From

¹³ More night terrors. These started occurring when I was in an abusive relationship—I would wake up to find the desk lamp on the side-table on. My girlfriend at the time would be sitting in the chair, staring at me, motionless, and silent. This was a frequent occurrence.

the kitchen I can see through the windows in the sun-room. There's a faint pre-dawn glow outside, and it fades as it stretches upward from the horizon. The sky is very deep blue, a shade of blue that's so close to black it's almost impossible to tell. The warmth spreads to my head and limbs, it fills me and my body seems to grow larger. I stare out at the snow covered hills behind the house; the sun is just about to rise.