# This Story Doesn’t Have an Ending

Before diagnosis, my wife spends a year making appointments for our daughter with different specialists. I think she's wasting their time. Emily has headaches? I had headaches at her age too, surely she'll grow out of them. My wife disagrees, but her family treats even minor bruises with ice packs and arnica oil. She schedules another appointment, this time with an endocrinologist. I don't know what an endocrinologist does, but am sure it's not this.

“My daughter has headaches,” I say, annoyed that I'm the one sitting in his consulting room explaining this.

“I hear a gurgling in my ears,” Emily adds.

He x-rays her hand to assess her bone development, measures her height, asks a few questions. He seems as puzzled as I am as to why we are here. I take Emily home, determined to discuss the topic of over-medicalisation of common ailments with my wife.

An ophthalmologist picks up the first clue when he detects pressure on Emily's optic nerves. He advises my wife to take her to the paediatrician's as soon as possible. The paediatrician sends them to the hospital and phones ahead. My son and I go out for pizza until my wife calls and tells us to come.

I live in Switzerland and I hear Emily’s diagnosis in French. They have found a lesion on her cerebellum, a contrast, a something-that-shouldn't-be-there, a shadow. They are not sure what it is and must operate, soon if not immediately. Whatever plans we have must be put on hold.

We were looking forward to Emily's thirteenth birthday. It is a few weeks away and have booked a log cabin in the woods for her and her friends. Instead, we must contemplate the possibility that she may not be around to celebrate it. The thought is too overwhelming to consider, so we shy away from it, tightening our focus to the next thirty minutes and spending our energy on remaining positive, calming our children, working out logistics until there is not enough spare capacity to consider the future The reckoning for me comes later; the acknowledgement that, left up to me, my daughter would still be on painkillers. Her headaches, which surely everybody has, would have killed her.

More doctors arrive and my wife and I try to impress their names and titles into our memories, hoping they will reciprocate and take their responsibility to our daughter personally. Yet there are so many of them, and their specialities require deciphering so much unfamiliar vocabulary, that I end up distinguishing just one or two from their white-jacketed colleagues.

I look up Dr Marwan* on the hospital website, needing to know more about this person before trusting my daughter to him. I find it reassuring that he has practised in France, although I have no idea why that might be. What does a paediatric neurosurgeon look like? Like this, apparently, sitting on the edge of Emily's bed in front of an audience of junior surgeons, wearing a chain and a black turtleneck sweater under his white coat, one leg crossed over the other, a leather shoe pointing at the ceiling.

I once heard a neurosurgeon on television describing his job as a blood sport and I examine Dr Marwan for signs of the predatory. He seems empathetic, kind even, yet I wonder if his calm demeanour betrays a certain ruthlessness. Even if it distresses me, I understand its necessity. It's the quality you need when darkened rooms and aspirins have failed and you must open the back of a child's neck and tunnel through her brain to a tumour.

We sign his consent forms, skimming the list of possible side effects, as if by denying the dangers of the operation we can negate them. Other children might wake up unable to speak, but not Emily. Her operation will be successful and she will suffer no ill effects. Yet cancer is a little like growing old, you gradually say goodbye to things you thought would last forever. If she survives, but with concentration difficulties, then I could live with that. With the kind of paralysis you might see in a stroke victim; surely that's reversible. In this internal negotiation I can only bargain downwards. I just want my daughter back alive. I do not care what state she is in.

We meet Dr Domizia, the childhood cancer specialist with the stubble and the knack for making the complex appear reassuringly possible. I am curious to know what kind of person chooses to work in paediatric oncology, but he does not mention this information on his CV. He warns us that, after they have removed the tumour, it will take a few days before they can determine whether it is malignant and or if it has spread. He refuses to guess in advance as it creates expectations. That does not stop me parsing his words for a hint, hoping that the true meaning will drop into my palm if I turn them over and over for long enough.

The operation is slated for the Sunday, or maybe the Monday or Tuesday. We stay beside Emily's bed to keep her company. My wife rings when I go to buy a chocolate bar.

“They're taking her down right now.”

I help steer the bed down to pre-op where we change into scrubs and I fight to get the elasticated plastic over my shoes with fingers that suddenly refuse to work. A parade of increasingly senior anaesthetists come in to ask Emily questions and tell us that they are in charge. The last one speaks with a folksy accent and the benevolence of Father Christmas. You would trust your daughter to such a man. I did.

We say goodbye with jokes and kisses and smiles on our faces. If this is the last time we'll see each other then we want to make the memory a good one. Emily has been growing her hair for months and it falls past her shoulders. It is the same hair colour as mine used to be, dark brown turning to black. We know they will shave it.

“See you later, lovey.”

She sticks her tongue out, I pull a funny face, and we watch Father Christmas wheel her away, holding back our agony until after we have deposited our scrubs in the big, black bins and found somewhere private to lose our minds.

One our closest friends is an anaesthetist, and she sends us a message in the early afternoon.

“Everything's going well, but they're going slowly. It'll be finished later this evening.”

We haunt the day room. Parents with kids having their appendix out get the hard chairs. We allow ourselves the luxury of taking over both sofas. Nurses give us tokens for the coffee machines and passes for the staff cafeteria. They call at 11pm. My wife answers after the first ring.

“Everything went well. You can visit her now.”

We take the lift to the fifth floor, which feels like a basement because the hospital is built into the side of a hill. It's like the underworld down there; strangers walk past each other along green corridors lined with empty beds and lit by neon strips, corridors that seem to get longer the further you walk down them. We enter a door marked *Soins intensifs médico-chirurgicaux de pédiatrie.* Paediatric Intensive Care.

Emily is in a bed surrounded by doctors. They are performing neurological tests on her and administering drugs. Painkillers, steroids, anti-inflammatories, antibiotics. What I take to be dry blood on her chest is a scrape where something has been pressed with force against her chest. Her neck is bent at an uncomfortable angle and her head is swathed in a bandage.

“Hello, darling.”

She doesn't open her eyes but her lips twitch.

“*J'ai soif,*” she says.

She can talk.

“What's that?” I say, wanting to hear her voice again, to confirm she can still speak.

“I'm thirsty.”

A nurse hands my wife an over-sized cotton wool bud and a glass of water and she swabs the inside of Emily's mouth. The room is partially lit by some under-counter strip lights. A monitor reads her heart rate, blood pressure and something I don't understand. Its alarm sounds and the numbers start to flash. Red, yellow, blue. The nurse studies it and, finding nothing urgent, silences it.

Emily spent her first nights on Earth in a similar ward. That time I pushed my hands inside her incubator and gently rubbed her stomach while I spoke to her through the perspex. Incredibly to me, she stopped crying. This situation has the same urgency, only this time there is nothing I can do. Even if I could push past the doctors, she seems so fragile I am afraid to touch her in case I break something.

I sense the other children in this room. I don't want to look at them as acknowledging their suffering would add an extra layer to my own. My duty is to stay, but the tension is unbearable, and I can feel the weight of the floors above me pressing on my shoulders. I start to panic and leave as soon as I can, to get back to my son, to contact our extended families, to not watch my daughter struggle for life.

I don't remember every night, but I remember one night when Emily had been moved to the high dependency ward. The nurse calls me, 'Papa,' and enlists my help.

“Give her that, Papa.... Hold this for me, Papa.”

Emily's head is at an awkward angle. It had been in a clamp for seven hours and her neck muscles have seized. It will take weeks of physio before it’s back to normal. Unbeknownst to us, she also has a fractured skull where the clamp's teeth bit too deeply. Later in her stay, cerebrospinal fluid will leak into her pillow. That night I spoon-feed her cold apple purées to soothe her throat and, once the nurse leaves, settle down to watch her while she falls to sleep.

The alarm sounds on her monitor and the nurse returns. He notes the readings and leaves again. This happens any number of times. I feel the panic return. My brother calls.

“What are you doing, Matt?”

“Willing Emily's heart rate monitor upwards.”

A doctor arrives and we have a hushed conversation at her bedside. It is one of the drugs she is on. It is depressing her heart rate. There is nothing to worry about, he tells me, as he recalibrates the monitor. I want to accept his assurances and yet my daughter's life seems to be in the balance. Should I trust him and the science I’ve always respected, or should I kick up a fuss until every senior doctor available has assembled in my daughter's room and agreed with this diagnosis? I wait a while, chiding myself for my indecision, wondering if I am watching my daughter pass away before my eyes. An hour passes, then another one. The alarm doesn't sound. I leave when I am sure she is safe and am left to wonder if, despite what I had previously believed, the act of dying might actually be banal.

I bump into Dr Domizia in a corridor late on the Friday afternoon following the operation.

“I’ve been looking for you. Emily's lab results are back in time for the weekend,” he says.

I appreciate his consideration and we find an empty room and sit facing each other.

“The news is good. Emily's tumour was benign and the surgeons believe they got it all out.”

I grip his elbow. He stops talking and fishes a tissue from a box on the table.

“It was a low grade childhood astrocytoma. It's a very common tumour in children.”

He knew beforehand. I am sure that he knew.

He writes down the tumour's name for me in case I want to look it up. I put the piece of paper in my pocket and tell him that if I have any questions I will ask him rather than trusting something I read on the internet. I keep the paper though, just in case.

I go to tell Emily the news. Her Aunt Glenda is there. She has probably come up to pray, which makes things a little awkward as, at best, I consider myself agnostic.

“I've got good news,” I say. “Your cancer is benign, which means it's not going to spread, and Dr Marwan thinks he got it all out.”

Aunt Glenda takes this as a sign that God has cured her and starts to praise Jesus' name. Emily and I hold each other as tight as we can and weep in relief. Later Aunt Glenda asks me how I think the tumour got there. According to her, the devil put it there and only God can remove it. I say that Dr Marwan is at least nominally Muslim, what does that mean?

Emily stays in hospital for two weeks, complications from her fractured skull delaying her discharge. I help out when they change her dressing for the first time. They have to take her head off her pillow, despite the pain in her neck and the way she holds it down and twisted to one side. I keep her nightie up and watch them swab her scar. On another day I sing, “Baby Shark” while a nurse pulls a catheter as long as my forearm out of her shoulder. I watch needles go in and stitches come out and like any parent of a chronically ill child, I have scars where no one else can see them. One day I may even forgive myself for fleeing intensive care.

My wife and I take shifts beside Emily's bed and, in the quiet times, I sit on the hospital's balcony and stare across the lake towards the muscular outline of the Alps. The clouds start to fascinate me, and I buy a handbook which names their formations and allots scores for spotting them.

“Altocumulus lacunosus,” I say in geeky self-mockery and award myself 20 points. Later I discover something deeply relaxing in sounding out their Latinate syllables without the need of the book. Emily takes an interest too and we watch them unfurl across the sky as we eat supper together on her last evening in hospital.

She celebrates her thirteenth birthday a couple of weeks later and my wife and I cry in the kitchen when her friends sing, because now even simple words like, “Happy Birthday, Emily” come freighted with significance.

We go on holiday to another lake and watch Emily and her brother chase each other through the waves. One day, when we are walking back from playing mini-golf, I glance at the sky and see the rarest cloud of all, the Kelvin Helmholtz instability, that has scooped the edge of a larger cloud into a row of whipped ice-cream tips. The book values its worth at 100 points.

“Look!”

I point at the sky, wanting my family to not only see it but confirm that my sight is not coloured by wishful thinking.

“Yes!” Emily shouts and turns to me with shining eyes.

It is there and it is gone. It feels like a sign, that everything would be OK because we are middle class, thoughtful people who feel guilt when we fly, eat more vegetables than meat and pay attention to our surroundings.

It was a sign, until it wasn't. Emily’s next MRIs turns up a growth in her brain, which Dr Domizia describes as a residue from the original tumour that may grow, may not grow, may stabilise or even shrink. If it does grow we can wait, consider surgery, chemotherapy and/or radiotherapy. He puts the odds of it growing at 50%.

It grows. Of course it grows.

We restrict this information to our closest friends and extended families. We turned outwards after Emily's initial diagnosis, towards our community. This time we turn inwards. I am not sure why. We are worn out by it. Are we wary of wearing other people out too? Or is the story becoming too complicated to describe in a single sentence? There might be a small element of shame in there, possibly failure too. So many people supported us the first time around and still she is not cured. Can we really ask them to expend the same energy a second time?

I look up Emily's tumour, not curious so much as looking for reassurance. The website tells me that 95% of children are alive five years after diagnosis. I discuss this statistic with a friend of mine, the husband of the anaesthetist who called us during Emily’s operation. Their daughter was diagnosed with malignant ovarian cancer as Emily was leaving hospital.

We take his boat out on the lake and talk about the clouds while our sons jump in and out the water.

“A 95% survival rate seems pretty low to me,” I say.

Of all my friends, he best understands the terror which lurks behind my question.

“No one can tell you the odds for your child,” he says.

We monitor this new tumour through regular MRIs, until the day Emily tells us she would prefer another operation to the tension of waiting to see if it will stop growing. She wants to be well and get on with growing up like a normal teenager. There is no rush, so we delay the operation until the end of the school year.

This time around we have months to prepare for it. Sometimes we read side-by-side, other times we kidnap each others’ teddy bears and demand wild and ridiculous ransoms for their safe return. Walking home one day, I see a giant inflatable unicorn in a shop window and buy it on a whim, then call my kids to carry it across town for me.

We try not to think about it. It is all we think about.

Her operation starts in the morning. We have already signed Dr Marwan's consent forms listing the possible side-effects. We understand that Emily faces a higher probability of suffering from these second time around. We are no longer in denial. Her brain functioning might well be impaired. She might suffer from paralysis. We prepare for the fact that she might not come back to us.

My wife calls the hospital in the afternoon, long after the operation should have finished. We are waiting outside by then, sitting on a low wall between the car park and an office block. I watch her face as she is transferred again and again between departments. This seems like the worst-of-all scenario. A nurse comes on the line from paediatric intensive care. My wife angles her head into the phone as she listens.

“Emily's awake...” she says, relaying the news.

We break down outside someone’s office window – she is not dead....

“It went well. She asked the nurse if she came from Quebec.”

– ...and her brain is functioning normally.

“We can go and see her.”

We return to the underworld and find Emily lying in bed with a nurse watching her from across the room. She is fully concious. There are no doctors pressing in from all sides. No alarms. Sunlight comes through the window. It is oddly peaceful. We wait for the hammer to fall – for her brain to swell, her heart rate to drop - and it does not. She leaves hospital a few days later. No complications, no rick in her neck.

I wish I could say, “No cancer,” but I'm not quite ready for that. English lacks a mood tense like the French subjunctive that expresses the hope that something that happened in the past is no longer occurring, and the fear that it still is. I do not have a certificate stating, “Your child no longer has cancer,” which I can hang on the wall and refer to in times of doubt or when I wish to congratulate myself on the way I handled things. The best I can say is my daughter does not have cancer until we get the next MRI results back. She is in remission until at least 19th October..

Aunt Glenda believes that if you say a prayer then God will take your worry from you. As comforting as it would be to believe this, my own faith is more complicated. Waiting with my wife in the paediatric oncology ward for Emily's latest MRI results, I watch a boy and his father leave a meeting room. The boy has a scar on his head which starts above one ear and crosses his skull to the other. He climbs into a wheelchair as his mother, Dr Domizia and Dr Marwan follow him into the corridor. Dr Marwan comes over to shake our hands and ask about Emily's health. Behind him, the mother leans against a wall. Her brave face melts away and she begins to sob in anguish. Dr Marwan crosses the corridor to place his hands on her shoulders and console her. I realise that people exist who are as capable of opening a skull as they are of showing compassion, and I choose to put my faith exactly at this point – not in God, per se, but in the wide embrace of human experience that can place two contradictory ideas side-by-side and make sense of them both. I have not been to church for years, yet before Emily's first operation I begged Him to spare my child. I do not believe in God, yet there are no atheists on childhood cancer wards.

Emily returns to hospital a few weeks after her second operation to have her appendix removed. As we wait in pre-op she demonstrates the quickest way to attract a nurse's attention is by disconnecting her heart monitor. It is only now, three years later as I try to make sense of Emily's illness, that I picture the two of us smothering our laughs in the midst of so much seriousness. There was something delightfully mischievous in this experience, an expression of *joie du vivre* in the fullest meaning of the term.

Life has stared me in the face so long that often I don't see it, so I write myself these words to unknot the unknown and to keep this *joie du vivre* in front of me. Dying might be banal, life doesn't have to be. Cross on red, talk to strangers, start a food fight in the high-dependency ward. Meet pettiness with joy, and never forget that 'None of the Above' is a perfectly acceptable answer.

*Names of doctors and aunts have been changed