

I AM, I AM, I AM

~~no more trying: there would be no more babies in our house.~~

~~I came home and cleared out the garage: all the baby blankets, Moses baskets, maternity clothes were packed off to the charity shops. I'd had a child and I would have no more. It was finished, that chapter of my life. It was over, it was done, and I needed to come to terms with that.~~

~~But something was wrong. My body had done its initial expulsion, after the IVF, then nothing. It seemed to be on hold or waiting for something. Ten weeks since the IVF ended, then eleven, then twelve, and still no period. So I went back to the clinic, which I of course now loathed, and saw the doctor, yet again, and he sent me for a scan - 'to see what's happening' - and as they rolled the scanner over my belly, there it was. An alert, active form, limbs waving frantically, as if to attract attention, a heart that was pulsing and pulsing, turning from light to dark and back again.~~

~~The doctor gasped. The nurses covered their mouths, then began fluttering anxiously through my file. How had this happened? they asked. How had this embryo held on, despite no signs of pregnancy, despite the heavy bleeding, despite the loss of its twin, despite a negative blood test, despite all evidence that the embryos had left, departed, drifted loose?~~

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Excerpt from I am, I am, I am
DAUGHTER by Maggie

~~-But there she was, despite everything, thirteen weeks -
of gestation under her belt and waving at us for all she -
was worth-~~

~~START HERE "Maggie is pregnant"
a little IVF treatment"~~
My daughter was born six months later, in early spring. She was small, wide-eyed, otter-soft, with a nap of white-blond hair covering her head. When anyone took her from me, she wailed as if her heart might break. The first night she spent curled on my shoulder, very quiet and still. Every time I looked down at her, her eyes were half open, looking back at me, as if checking I was still there, that I hadn't gone anywhere.

In any fairy-tale, getting what you wish for comes at a cost. There is always a codicil, an addendum to the granting of a wish. There is always a price to pay. How was I to know, as I held her that night, as I stared at the ultrasound screen, as I burst out of the clinic, fumbling with my phone, trying to press the right buttons so I could call my husband, the boy from the courtyard, and say, you'll never guess what I've just seen?

How I've longed that it could have been me, the wisher, who had to pay the magic's price, to bear the brunt. I would give anything to take the curse from her, to transfer it to my own shoulders. But, as it is, I must stand by

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every last crevice of her, from the joints of her toes to the innermost crease of her ears.

When people stepped up towards the pram that spring, eager to see the baby, I found I was gripping the handle, bracing myself. Please, I was silently willing them, find something nice to say: compliment her blue eyes, her blonde curls. Don't reel back in horror. Don't gasp, what's wrong with her?

When I think back to those days, I am overcome by an urge to go up to the person I was then, put a hand on her shoulder and say: you have no idea what is coming. At that time, you see, I still thought it was something that could be sorted out. It was only eczema, wasn't it? How bad could it be?

Some things I didn't know, as I pushed her red pram up the hill: that there is no known cure for eczema. That even though her skin seemed as bad as it could possibly be, it would get an awful lot worse. That eczema, at its most severe, can be dangerous and even life-threatening. That her skin would torture her every minute of every day. That it indicated much more serious health problems for her.

By the time she was almost nine months old, she had seen the health visitor, who had referred her to a GP, who had referred her to a dermatology nurse, who had

while the innocent, the child, the baby must be the one to suffer.

And suffer she does.

On the second day of my second child's life, when I was still wired up to a drip-stand, woozy from anaesthetic, I removed the sleepsuit the nurses had put her in. My hands shook, with the novelty or the drugs, hard to say which, and as I eased the suit away from her there was a shower of something the consistency of snow. Suddenly my lap was dusted with white.

Odd, I thought, then tossed the sleepsuit aside and forgot all about it.

That was the first clue.

When doctors ask me when she first developed eczema, I say, she was born with it. A week later, her skin was peeling off in strips, like dried glue. The cuffs of jackets seemed too harsh for the petal delicacy of her; the circle-backs of poppers and the undersides of zips were a metallic outrage, printing her with red, raw lesions.

Her skin never looked like skin should. It was patchy, hot, sand-dry, crepy with inflammation. By the time she was a month old, she was encased in the livid, raw body-cast of eczema. Her skin split open if she flexed her wrist, her arm, her leg; the disease had invaded every millimetre,

same paraffin-based emollient the health visitor had given me when my daughter was five weeks old. It had made absolutely no difference.

When I was in my twenties, still trying to find the right path in life, I used to have a particularly vivid recurring dream. It came in phases, this dream, but always with the same scenario, the same setting, and usually at a time of flux or upheaval. It would make an appearance, rising from my subconscious, if I was moving, yet again, from one dodgy and damp flat to another, if I had a new job, if I'd left a man or if a man had left me, if I'd received some awful news, if something bad had happened to someone I loved. Always at these moments the dream would resurface, often for several nights in a row.

In the dream, I would be walking along a track and ahead of me would be a child, a girl with fair, curling hair. Always, she was crying. I could see that her thin shoulders were bent in distress, her hands wiping at her tears, her feet stumbling as she walked.

I would always attempt to catch up with her. Sometimes this was allowed to happen; at others, I tried and tried to reach her but the distance between us only increased. If I managed to get near her, I would lift her up and carry

referred her to a consultant dermatologist at the big London hospital where she and her brother were born.

On my way out of this appointment, I bumped into my friend Constance. She took one look at me, standing there on a pavement, and asked what on earth was wrong. I sat down on a low wall, holding on to my daughter, who was scratching and writhing and bleeding into her clothing, and wept. Constance took the baby while I told her how we had waited forty-five minutes to see the consultant, and when we walked in she was already writing something on a pad. I had assumed it was some notes for her preceding patient but then the doctor had ripped a sheet off her prescription pad with a flourish and handed it to me before I'd even sat down. 'There!' she'd said. 'The good news is that, at this age, they haven't learnt to scratch!' She didn't examine my daughter; she didn't ask me a single question; she didn't even glance into the pram. If she had, she might have seen my tiny child sandpapering her wrists against the straps of her harness, she might have seen a baby covered from crown to foot in open, weeping abrasions, she might have seen the desperate, weary, tortured look in my daughter's eyes — a look no nine-month-old should ever have.

As I'd taken the lift down to street-level, I'd glanced at the prescription and had seen that it was for the very

vast, prickling with starlight, the vista so enormous I fancied it was almost possible to see the curvature of the earth.

I remember thinking, as I stood there, alone in the desert night, that the child must have been me: she looked, from the back, just as I had done, with her slight frame, her pale hair, her outpourings of emotion. I must, I reasoned, have been trying to catch up with a younger version of myself, to comfort her, to tell her that everything was going to be all right. But was it? I asked myself, as I gazed out at the desert. Was it going to be all right? I had no idea.

I believed this interpretation for years: that these nightly visions were a subconscious meeting between my adult and child self. Now, though, I wonder if it wasn't my daughter ahead of me there on the path.

She and I share certain physical characteristics; our likeness is often commented upon, by friends and strangers alike. Photographs of us at the same age could be interchangeable, if you ignore the 1970s nylon outfits I've been zipped into. A shaky, discoloured film of me, aged five, at a street party, made her once exclaim, with absolute conviction, 'There's me.'

I've never had those dreams since. They vanished, evaporated, along with the other ephemera of my twenties:

her, sometimes on my back. I can still recall the dream-sensation of her arms gripping my shoulders.

For such a little child, she was heavy, as if her suffering weighed down on both of us. If I managed to reach her, if I took her into my arms, she would stop crying: I was always aware of my ability to bring about this change. Sometimes I would jerk awake, suffused with panic, knowing I hadn't been able to help.

The first time I ever had this dream was in the middle of the night on the Trans-Siberian Railway, as I was winding my way back from China, aged twenty-two. I remember waking with a jolt, sitting up in my bunk, clutching my sleeping-bag around me and looking about the compartment, as if the child might be standing there, waiting for me.

She wasn't.

I climbed down from my bunk, tiptoed past my cabin-mates, who were sleeping below me, and out into the corridor. The train was swaying and clanking through the night, pulling us north as we slept, away from China and through Mongolia. I looked out at the Gobi Desert, which was sliding by the windows, pressing my fingertips to the glass, trying to grasp at the disappearing threads of the dream: the girl, the track, her grief, my overwhelming compulsion to help her. The sky outside the window was

grass, leaves, food, toys, perfume, soap, smoke, sand, concrete, mud, water, juice, ropes, elastic, clothes, dust, mould. They cannot concentrate on anything for longer than a second or two because the pain of their skin is so extreme, so distracting.

I have never known anything like it. I had not thought

such suffering, such torture, was possible. Walking around the rooms of my house, holding this miserable, wailing baby, I had no idea what to do. I put on the ointments given to me by the doctor but they didn't work – they didn't even come close. I couldn't believe such a

condition was allowed, that such a thing could happen. What, I wanted to howl, to the walls, to the carpets, to the chairs, the hell do I do? I wanted to lodge a complaint, raise an objection, with somebody somewhere. I was frequently seized with an urge to run with her into the streets, to stop passers-by, to offer up my daughter to their gaze and say, look, do you see that? Have you ever known anything like it? Do you know what to do? Can you help her? Can you help me?

I had no idea how to live, how to be, how to bear witness to this level of agony in a child so young, how best to alleviate her pain.

I would put her down in her cot for a moment, so I could make a drink or a snack or even go to the toilet.

the dreary rental flats, the uncertain and mind-shrivelling jobs, the late-night urban wanderings, the last buses, the monthly travel passes, the skipped meals, the ill-judged boyfriends, the pressing calls made from phone-boxes, the clothes (the insubstantial dresses, the T-shirts so short as to display the whole midriff, the trousers that rode low on the hipbones), the sincere and strenuous efforts to persuade adults older than you that you indeed could do what they needed, you definitely could, you were sure you could, all you needed was the chance.

Did my daughter appear to me a decade and a half before she was born? I like to think so. There she was, looping back through time to brush past a person not yet ready to be her mother – nowhere near ready, if I'm honest – tipping me the wink that she would one day arrive in my life. Readying me, perhaps, for the road ahead, sowing the seeds for all the strength, compassion and resilience required for her existence.

It's hard to articulate the level of care and patience required to look after a child with chronic eczema. These are children who are distressed and uncomfortable every minute of every day. They don't sleep, they can't eat, they can't play. They find clothing unbearable. Everything makes them itch – heat, cold, wool, sofas, animals, wind,

Constance interrupts: 'You can't go on like this. And neither can she.'

I look down into my daughter's face, at her sentient blue gaze, at her broken and inflamed cheeks and forehead, at the infected and weeping skin of her neck, at the blood-stained sleepsuit.

I take down the number. I make the appointment. I pay the two hundred pounds. Within days, we are sitting in front of Dr Fox (no waiting list, no unexplained delays). He asks about my daughter's birth, her diet, my medical history, my husband's. He smiles at my son, who is sitting in the room with us, and says, 'No eczema there, I see.' He asks me to undress my daughter and when I do his face turns carefully expressionless, professionally contemptive. He lifts her arms, he examines her wrists, her legs, her torso, handling her with the gentlest of touches. He writes a list of what we should use: bath oils, soap substitutes, steroids, moisturisers, anti-bacterial ointments, detergent-free shampoo. He refers us to his NHS clinic so that we won't have to pay next time. He gives me a sheaf of leaflets about sensitive skins, sun-creams, laundry, specialist eczema clothing, silk gloves, closed-end pyjamas. I am thanking him, getting up to leave, when he says, 'I'd like to run some allergy tests. Just in case.'

I'm taken aback. I almost say, let's not bother. Allergies

Halfway through this task, I would be summoned back by screams, to find that, in my brief absence, the bedding, the cot, the walls, the baby were now covered with blood because she had been driven to scratch herself, to tear off her clothes, to flay her own skin. I would lift her out, soothe her, cover her in emollient, put her into a clean outfit, change the sheets, load the soiled clothes and sheets into the washing-machine. I would try to stay calm, to remain positive. Look, I would say to her, laying her down on her play mat, a ball! A rattle! A lovely book, a squeaky duck! And then I would watch as she turned away, letting them fall from her fingers, curled into herself, started to rub her arms on the surface of the mat, seeking relief, seeking release, seeking any sensation other than the misery of her condition.

The day after the awful appointment with the consultant dermatologist, I am, for the twentieth or thirtieth time that morning, trying to smear my daughter with cream so that she can manage a feed, when Constance phones. 'I've found out who you need to see,' she says. 'He's called Dr Fox and you'll have to pay but he's the best. Everyone says so.'

'I don't know,' I mumble, tossing bottles and pots of lotion back into the basket under the sofa. 'Private health-care, I'm just not sure if—'

Your lives are conducted with a constant background hum of potential peril. You begin to experience the world differently. You may no longer go for a walk and see a garden, a playground, a farm full of goat kids. You must always be tabulating and assessing risk: that pollinating silver birch, those food wrappers in the rubbish bin, those flowering nut trees, those gambolling dogs, shedding their dander and fur into the air. You school yourself, quickly, to keep your anxiety, your levels of vigilance tamped down, concealed, to maintain calm, to speak in a modulated voice, even when you are so gripped with panic that you can't hear anything other than your pounding heart. On seeing the approach of someone holding a chocolate hazelnut dip, you say - lightly, evenly - let's go over here, when part of you really wants to scream, run, run for your life.

You become ferociously, uncharacteristically organised: there are prescription lists to update, expiry dates to note down, letters to write, governmental departments to be phoned, internet searches to conduct, medication to be filed and bagged, symptoms and triggers to be recorded, forms to fill, receptionists to call, medical papers, reports and trials to keep abreast with, appointments to make, medical kits to be taken out of one handbag and stashed in another because what you must never, ever do is leave the house without it.

haven't been mentioned before now, by any of the other NHS medics she has seen. She has, so far, consumed only milk and a bit of pureed vegetable. Allergies are not on my radar. I don't have any and neither does my husband or my son. But because this doctor has been so good, so attentive, so careful with my daughter, I say yes. Of course I do. What other choice do I have?

I don't need to say, do I, that the tests came up positive, instantly and unequivocally? That she was allergic to a long list of things, several of which could tip her into dangerous, lethal anaphylaxis. That in the graphs, her immunoglobulin E levels were registering up in the grey areas, the off-the-scale areas, the worse-than-severe. That in that moment our lives tilted to a new angle. That, looking at the results, I couldn't believe I'd been walking around the world with her in a state of horrible ignorance. (But I took her to Africa, to a remote Swedish island, I wanted to shriek, as if volume alone could retrospectively undo these acts.) That, within minutes, we were in a room with a training nurse who was showing my husband and me how to inject adrenalin into the thigh of a rubber doll.

FINISH HERE

The effects of living with a child who has a life-threatening condition, of loving someone who could, at any moment, be snatched from you? I think about this a lot.