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raising her disabled son
and the life-changing
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‘A gripping and vital insight into the lives of families
trying to thrive in bureaucratic systems that all too often
add to the challenges of providing disabled children with
basic care and human rights. Impossible to put down.’
Dr Hannah Barham-Brown, deputy leader of the
Women’s Equality Party

‘Rooted in love and is a moving story about the
transformative power of adapting, practically and
emotionally to changing circumstances. As a disabled
adult, it was a joy to join the parent of a disabled child
as they embrace Disability Culture and allyship.’
Jess Thom, Touretteshero

‘A courageous, heartrending story of grief, love
and ultimately hope.’
The Sun, 5 star review

The CRACKS that let the LIGHT IN

A mother’s story of raising her disabled son and the life-changing power of books

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For James, without whom there
wouldn't be these children,
and it would all be less fun.

1

I had been in labour for many hours when I am told my baby Ben is in distress and needs to be born immediately. His heart rate is low, they say, and there is no time for local anaesthetic.

There is a sharp pain and out he comes. He is immediately cut from me and carried over to a plinth where midwives lean over him, suctioning and murmuring. There is silence apart from low, urgent conversation between midwives and then doctors. People hurry in and out and pay my baby close attention. Where there should be the sound of a baby crying there is nothing.

I know very little about the realities of childbirth but I know a baby is meant to make some noise. Something has gone horribly wrong. After hours of gas and air and contractions I feel detached while also very present in a body that is tired and hurt.

I have a thought that is sharp and brittle: this might not be OK.

'He's not making any noise,' I say to James.

I haven't yet seen Ben when he is taken away to intensive care in a flurry of medics. I am told he had been born unresponsive but has been resuscitated. He now needs specialist help. It is serious. James steps out of the room to call my parents.

After my mum and dad arrive, a doctor comes in and stands at the end of my bed while James holds my hand. 'I think that at some point during your labour your baby didn't get enough oxygen. He is now very sick,' she says.

I ask to visit Ben and, since I can't yet walk, my bed is pushed along bright corridors and through doors to the neonatal unit nearby. It doesn't feel right to be travelling through the public areas of the hospital, passing the relatives of other labouring women, in the bed I have just given birth in. I check I am fully covered with a sheet.

Two midwives squeeze my bed into the room where my baby is lying on a cot, very still, plump, not yet clean and covered in tubes. I am not allowed to touch him. I don't know what to think.

I have still not delivered the placenta so, after returning from seeing Ben, I am taken to an operating theatre to have it removed. As the doctor finishes the procedure and I am being stitched, the anaesthetist speaks to me kindly, holding my hand, and I realize that I am a person who should be treated sympathetically.

I arrive in the recovery room and am told that my baby needs to be transferred to a different hospital with expertise in a particular cooling treatment that this hospital doesn't have.

This cooling treatment may help minimize the damage caused by oxygen deprivation.

'Can I see him before he leaves?' I ask.

'I'll see what I can do,' the neonatologist replies. 'I'll speak to the transfer team.'

Ben arrives a while later in a different cot to the one I had last seen him in, surrounded by machines and tubes, pushed by a team of four people who will keep him alive for this journey. Their uniforms look professional and urgent. I can only just see Ben through the medical equipment surrounding him. They manage to manoeuvre his cot close enough so that when they open a small window in the side, I can hold his tiny hand for the first time. I didn't know that this was how a birth could go. I don't feel prepared for any of it.

Later, in a private room, I will my legs to recover from anaesthetic as James sleeps on a hard sofa nearby. When healthcare assistants come to check me, they don't seem to realize how ill my baby is or that he has been taken away to another hospital. 'I need to leave,' I say. 'I have to get to my baby.'

I am consumed by a determination to go home because then I can go to Ben. My mother- and father-in-law have already gone to the new hospital and tell us he has arrived safely but I hate the thought of him being alone. When I can feel my legs again, I carefully lower myself off the bed and walk slowly to the loo. 'I have done a wee,' I say to the midwife who comes when I press the buzzer next to my bed, this being necessary to be discharged. 'Can I leave now?' I don't know how Ben is, or really what he looks like, and I need to be closer to him.

Once I am allowed to leave the hospital, my parents come to collect us. When we arrive at their house, Dad offers us roast chicken in front of the fire but I am so tired I can barely eat. I walk slowly upstairs and sleep deeply. The next morning, my mum drives me and James across London, putting a cushion on the passenger seat for me and trying to drive over the bumps as slowly as she can.

Ben is sedated and covered in sensors and wires. We can't hold him. All we can do is stroke the exposed areas of his skin and listen to the warning tones of monitors nearby while he remains silent and still. I stare at his face, imprinting his features on my memory. I have never been in an intensive care unit before. I am shocked to find myself here, grateful to hold my baby's hand but overwhelmed by the surroundings and his apparent delicacy.

For the next week, we visit each day to spend time with Ben. The immediate daily tasks feel onerous in my injured body. It takes concentration to get dressed, travel to the hospital, remember to eat, take painkillers, decode the monitors above Ben's head. We begin learning the language of critical illness but I refuse to fully engage. James has conversations with doctors about Ben's prognosis and translates parts for me. I just make sure I can turn up, hold Ben's hand, painstakingly collect my colostrum – my first breastmilk – in miniature quantities and hand them over to the intensive care nurses.

James says he is going to arrange an appointment for us to register the birth and when I overhear his conversation on the phone I realize a doctor has told him it should be done urgently. I know that there is often a long wait to get an appointment but James gets one quickly because, I gather, there is a risk Ben could die before we've had a chance to register that he has lived. James and I don't talk about this with each other.

Three days after Ben's birth, some of the wires and tubes can be removed and his breathing support reduced. After two more days, we can hold Ben briefly. James and I squeeze next to each other on an armchair with a pillow on our laps. A nurse carefully arranges the tubes and wires to one side and picks Ben up. She lowers him onto the pillow and I cradle him, unable to really feel the weight or shape of him through the pillow but grateful to be this close. James has one arm around me and the other around Ben's legs and we sit gazing at this wondrous child who we can just about feel and see among the paraphernalia keeping him alive.

As Ben nears a week old, it becomes more likely he will live. His breathing support is reduced again and some more of the monitoring wires are removed. We can hold him without a pillow and see his face. He has survived and I am so thankful – that he is alive, that I can cuddle him and that I don't have to monitor every breath in case the next one doesn't come.

We are taken into a small room to discuss the results of a scan of Ben's brain. A doctor quietly talks us through the events of the last five days and explains the likely impact of an 'insult' like Ben's, when the brain has been cut off from the oxygen it needs. We all face a computer screen and, as she clicks the mouse, we can see black-and-white images of our son's brain, metaphorical slices through skull and tissue.

The doctor explains what we are looking at and even our unskilled eyes can see that areas that should be dense are murky. She talks to us about the possibility that Ben's brain might not communicate with the muscles that control his body. The messages might not get through, or might speak in the wrong dialect. Ben's brain will likely speak a language that his arms, legs, hands and tongue cannot understand.

I am relieved that my baby has survived but devastated that he is injured. Afterwards, we pace the streets surrounding the hospital, me crying and James holding my hand. I am distraught.

As Ben's health improves he is moved to a different room within the ward with less beeping, fewer nurses and more light. Our families join us at the hospital each day. I want to be with Ben all the time, holding him, feeling the undeniable weight of him. If James or I are not with Ben then I want to know someone else is. I don't want him to be alone.

One evening, when he only has two wires or tubes attached, I am cuddling Ben when a nurse says, 'Careful! If you hold him all the time he'll get used to it and you won't be able to put him down!' That's exactly what I want, I think to myself. I wasn't able to hold him at all until two days ago and I am worried he doesn't know who I am. He hasn't yet made a single noise. All I want is for him to realize I am his mother, want to be close to me, and be able to cry if he's not.

When James and I leave the hospital after visiting Ben we bump into a friend. 'When are you due?' she asks as she looks down at my swollen belly. 'He's been born,' I say. 'He's ill in hospital.' She is aghast. 'I'm sorry. I had no idea.' I try to make her feel better before we go to buy a sandwich. I haven't spoken to anyone outside of my family. I have left social media and I don't check my email. I don't want to talk to anyone I don't have to. James fields messages and calls, and in the first month I will only see a few friends who have arranged to visit.

We are told Ben will be transferred to our local hospital when he is a week old but it is not clear exactly when this will happen. James calls the hospital just before we leave home one morning to check how Ben is. 'He's not here,' they say. 'He's been transferred. Did no one tell you?'

I feel redundant. My son was crossing the Thames in an ambulance with strangers and I didn't even know. I don't know what makes a mother, but I am certain I don't yet qualify.

We can now walk to the hospital each day. As I heal, I am able to walk faster and James doesn't need to support me as much, though we still walk close, arms linked or hands held. It snows and we change from wellies to indoor shoes by the lockers in the neonatal unit before we go in to see Ben. Compared with tiny premature babies, he looks solid and substantial but when we hold him he is small and floppy.

We hold Ben as much as possible. One night we leave my younger sister Maddy holding him while we go for dinner. When we return Ben is back in his cot and she is apologetic.

'I cuddled him for an hour,' she says, 'until I couldn't feel my hands any more. I was too scared to move but then a nurse came and helped me put him back.'

Just before Christmas we are taken into a small room with a neurologist, Dr M. I notice a box of tissues on the desk. The room has medical textbooks on the shelves and I wonder what happens in here when it's not being used to deliver bad news. Dr M has examined Ben's body and seen the scan of his brain which he confirms is insubstantial in places where it should be robust. He is gentle but factual, delivering bad news as kindly as he can. 'It isn't certain,' he says among other caveats, 'but it is likely he will have cerebral palsy.'

We are told Ben's physical movements will be affected, the most pertinent of which in that first month is his ability to control his tongue and swallow. A more junior doctor sits next to Dr M and says nothing but looks grave. Later I will marvel at how Dr M managed to deliver this uncompromising news to us in a way that didn't make me hate him, like I did with other medics in those early months who told me news I didn't want to hear. Dr M made me feel he could be our light in an otherwise gloomy tunnel – Ben's condition was serious, but he would do all he could to help us and all hope was not lost.

Ben's most urgent problem is his difficulty with feeding. I was trying to breastfeed him every day and though I didn't know how it was meant to feel, the slackness of Ben's mouth didn't seem right. James and I were also offering him a bottle, but he swallowed very little milk. I am so preoccupied with these tasks – breastfeeding, bottle feeding, expressing milk to a three-hour schedule – that there is barely time to think. However, Ben is getting almost all of his nutrition through a nasogastric (NG) tube. As he approaches a month old he is doing well – he now makes little noises and cries when distressed, his breathing is reliable, his oxygen saturation good, his organs stable – but it is his inability to drink that is keeping him in hospital.

Our only hope of leaving, which we are desperate to do, is to give Ben milk through his feeding tube and so James and I are formally trained. Forms are filled in and competencies checked. I want to be able to be Ben's mother rather than feeling like I am one person in a team who cares for him, and often the least important member. I want to be able to give him a bath, rather than watch someone else do it. I want him to realize I am the most important one. I don't wear perfume in the hope that he will learn my smell, or earrings so I can nestle him into my neck unscratched. When Ben is five weeks old, we are allowed to take him home, to look after him unsupervised.

But there is another problem. Our home, with our books, pictures and cats, is thousands of miles away in Qatar where James had been working as a diplomat in the British Embassy and I have a job as an architect. For the last three years we have been living in the Middle East – in Damascus in Syria and then Doha in Qatar. We were meant to be having a baby in London and then returning there but that now feels unlikely. So we live in my childhood home with my mum and dad.

James has to travel back periodically to his job in Qatar. My dad is a doctor which is reassuring and my mum is excellent in a crisis so she helps with everything, but I can barely keep up with the schedule of keeping Ben nourished. They are helping me constantly, and yet it is still a punishing regime.

We are feeding Ben through his tube and with a bottle through the day and night. When we aren't feeding, we are washing and sterilizing the syringes, bottles and pumping equipment. I'm too busy keeping my baby alive to have the time or space to enjoy him. I stop expressing milk because it feels like that is the one thing that isn't absolutely essential. When I answer the door to the postman bearing gifts from friends and cards of congratulation from around the world, I barely register them before I move on to my next task.

The feeding tube should stay in place, stuck to his cheek with a rectangle of plaster, for one month before being removed and a new one inserted down the other side of Ben's nose. But Ben's skin is sensitive so the adhesive dressing often comes away, or he grabs the end of the tube accidentally and it is pulled free. Occasionally he sneezes it out. Late one night, one week after bringing Ben home, I feel in Ben's wicker crib for the end of the tube and come across the entire tube buried under his body. I knew this could happen but I am still shocked. It needs to be put back before I can feed him so I quietly wake James and we pack Ben into his car seat, taking a new tube and an explanatory letter to A&E. We tell the nurses what has happened and they put the tube back down within half an hour. When we return to the house my parents are still asleep. I am thankful we live so close to a hospital and that it has been such a simple procedure, but I wonder how many more times we will have to do this trip. Is this what we do now – take our baby to hospital in the middle of the night so we can feed him?

To avoid this I learn how to put the feeding tube in myself so that we won't have to go to hospital every time it comes out. There is nothing nice to be said about pushing a small, stiff but flexible tube into your son's nose, past the resistance of the back of his throat and down his oesophagus. Ben waves his arms furiously while I'm trying to get to his face so he has to be swaddled and held down as he bucks in protest. Once the tube is in, someone has to hold it still on his cheek while I check it's in the right place by pulling back some fluid from his stomach and checking the pH, and then I attach pieces of pristine adhesive to his face and remove the guide wire from the tube.

I know some parents don't do this. They don't want to be their child's nurse when there are nurses that can do it. I want to do as much for him as I can, and if this is what it takes to ensure he is fed, I will do it. I thought I would nourish him with breastmilk but instead I must ensure he can be fed through a tube so I take that on fully, wholeheartedly. I hate putting the tubes down, but I want to be able to feed him. I want to be everything to him. I realize I will do anything for him.

In between the tube changes we change the dressing, which means pulling the old one off his cheek. This hurts and he lets me know it. Once, we left the tube on one cheek for a full month because we were so grateful that we hadn't had to change it but then the skin on his plump cheek took almost three months to recover. Ben will scream while I am adjusting or inserting the tube – he knows what's coming as soon as he's held down – but will then calm quickly once it's finished and he's cuddled. I can't decide whether it's awful that he has learned to anticipate something so unpleasant or good that he recovers quickly. I hope that I am cuddling him enough to counteract the discomfort.

His delicate, newborn skin means his cheeks are constantly sore. When I see other babies, I am taken aback by their smooth cheeks, by the fact that they've never had to have great wads of adhesive messing up their faces. When the tube falls out one evening, I give Ben a bath and remove the plaster. His cheeks are not too red and for a few hours I have an unadorned baby. He has pale skin – so pale that anxious medics sometimes ask us whether he is always this colour – and reminds me of an angelic cherub in a painting. I take a photo and it is the first photo I have of his face with nothing on it. When James gets back from work we spend a little while with our sweet baby before James wraps him in a towel and holds him down and I push another tube up his nose against his will.

One morning the tube falls out when James is at work and my parents are away. I phone a family friend who can walk to my house in ten minutes. She has never seen this done before but I trust that she is practical enough to be able to assist me without being overwhelmed. By the time she arrives I have

prepared everything I need on our dining table and found a large, stretchy sheet. I wrap the sheet round and round Ben so only his head is sticking out. I tell my friend she will need to hold him more tightly than she imagines. As I begin Ben starts crying and I hope his tears won't stop the adhesive sticking. It is a strange thing to ask someone to come and help you make your child cry and I am grateful for her stoicism.

The constant process of sticking, unpeeling, pushing and pulling is always done by me. I have to purposely cause pain to my baby in order to make sure he can be kept hydrated; filled up with milk like he's a car at the garage and therefore maintain those podgy cheeks and rolls of fat on his forearms. It is the only way to keep him alive so I feel I have no choice. James is not always there because of work; he doesn't offer to learn to do it and it doesn't occur to me to be resentful because I want to be needed. Of all the ways that motherhood is not what I imagined, the dependency is what I expected. James shares everything else – feeding, changing, comforting – but this bit is mine and, to me, it proves how devoted I am.

People are surprised by my no-nonsense willingness to get on with it. I put Ben's tube down when we have to make another trip to A&E rather than letting a nurse or a doctor do it. I pull the tube back a couple of centimetres in the middle of an X-ray room when they need to fill his stomach with Barium to check whether he has reflux. I put down three tubes in twenty-four hours when he coughs the first up into his mouth and tears the second off his cheek after a night of crying. All the time we are reminded of the danger – the possibility of the tube moving, going down into his lungs and them filling with milk. We live with a permanent backdrop of peril: the tube might come out and we won't be able to feed him; the tube might go down into his trachea and we will drown his lungs.

When we hold Ben he buries his face in our chests and rubs it from side to side. He can't get his hands to his face otherwise and I think this is him seeking comfort, itching the plaster on his cheek and enjoying the pressure. It feels good to him and leaves us with snotty swipes on the front of our jumpers. But I am constantly on edge, wondering if the nuzzling will dislodge the tube. I hate that the thing that he enjoys doing, that soothes him, is something that makes me anxious.

Keeping Ben fed requires a certain toughness of mothering. It is in the same territory as forcing children to take horrible medicine but it feels far more harsh and relentless. I have to be both nurturing and brutal. I hope that, surrounded by kissing and singing, cuddling and smiling, Ben remembers the good times and the horror will fade. Mothering, it would seem, isn't about making your child happy all the time. Sometimes it's about making your child cry because there is no alternative and hoping that he will forgive you.

One morning in the days after Ben was born, I had been in the kitchen with my mum. Ben was still in hospital. 'I just want to check,' my mum said, 'that you know none of this is your fault. You couldn't have done anything differently. You didn't do anything wrong.' I did know, though it didn't make me any less sad, and I cried, again.

I just don't understand how I have ended up in a situation where I'm feeding my baby by holding a syringe of milk above his head, attached to a feeding tube. I did birth preparation classes and they told me about the benefits of natural childbirth and breastfeeding. I had no idea there was a shadow world where you aren't sure your baby will live, then you don't know how to feed them, and every aspect of their life is unclear. I just don't know if everything is going to be OK.