

The Audacity of Hope

I realise that we've been sent to the arse end of the hospital. The ceiling is a smoky grey and the sickly yellow walls conjure images of curdled cream. The charcoal carpet insinuates – *don't dare to hope*. The beige blinds with the frayed edges spell out a coded message too – *Beware, this is not a room of lofty expectations*. Disappointment and fear hides in the mouldy black shadows that seep into the corners of this tiny room. The rays of sunshine that trickle through the windows reflect the shiny veneer of hope, that emotion that gives parents and caregivers the courage to take one step at a time into whatever the future holds.

Rory puts his palm tenderly on my denim skirt and raises his dark eyebrows at me. Willow, swaddled in a lilac blanket, sleeps in his arms. Apart from the nasogastric tube that snakes from her right nostril, down her throat and into her stomach, she looks like a perfectly “normal” baby. Except she isn't. She's a different type of normal. Her own shade of normal.

I smooth my damp hair, aware of my mother's scrutinising stare. She was horrified when she saw me this morning. I don't have the luxury of grooming myself these days. All of my time is dedicated to keeping Willow nourished and thriving. Every few hours, I pump my breast milk into a bottle, then funnel it into a syringe that attaches to the nasogastric tube, while holding Willow upright as my milk slowly flows into her stomach. All the while I'm hoping that she won't regurgitate my precious milk. All I managed, this morning, was a smudge of lipstick as Rory drove us here.

'Pippa, don't let yourself go,' Mum hissed in my ear, thinking that Rory couldn't hear her. He reacted by giving me a spontaneous kiss on my cheek, his reassurance that it's okay just to be coping, because he's in the leaky boat with me and we're both being pummelled by tidal waves of information that we're trying to process and simplify. Little chunks of what we can work with now and what we can do in preparation for what might be – in the coming months and years.

‘Do you have any other questions?’ asks the geneticist, Doctor Dalia.

Rory nudges me gently with his elbow. ‘Anything you wanna ask, Pip?’

I bring my attention back to this room, this appointment, and clasp my hands together.

‘Dr Dalia, you said that every person with a genetic condition presents differently, that many children show different features depending on the severity of their condition ...’ I pause, and wonder, *where am I heading with this?* Lack of sleep and stress have snatched away my once erudite mind. ‘Aahh, sorry, my trail of thought has gone.’ I mispronounce the medical term of Willow’s condition and then wave my hands around trying to bide time, to regain control of my thoughts, but all I have are threads of words and sentences that make no logical sense.

Marion White, the social worker who has been sitting silently in a corner, states the name of our daughter’s condition. It slides off her tongue in a detached, matter of fact kind of way.

‘Tongue twister,’ my mother mutters, rolling her eyes. Rory and I simultaneously lurch away from her. Rory has a tight frown at the corner of his lips. I give her a glare that could fire lethal missiles. Mum asked to come to our Tuesday appointments because she wanted to know more than we wanted to disclose about Willow’s condition. Unfortunately, Mum has a history of catastrophising, and her emotion radar is on red-hot-high right now. Tuesday clinics start early and seep into the afternoon. We have already had two appointments and still have four others to attend, with hours of waiting time in between. The last thing we need is my mother’s negativity shadowing us as we try to get through the day.

Willow groans and I put my hands out for Rory to pass her to me.

‘How are you handling everything?’ Doctor Dalia asks, her question edged with compassion.

I kiss Willow on the forehead, not having quite concluded how I actually am handling our circumstances. ‘We’re doing okay. This doesn’t change things. We don’t see her as ...’ I

don't want to utter the word 'disabled' because we've heard that word so often during Willow's five months of living, that Rory and I have made a pact not to say it, not to validate it. He gives me an encouraging smile and I straighten my spine. 'We hope to have more children and for Willow to thrive and grow her own way, within a supportive family.'

Mum takes a breath. 'I've been Googling the diagnosis – it's a devastating condition.'

I close my eyes and clench my jaw.

Dr Dalia purses her lips. Eventually, she speaks directly to my mother. 'It's best to wait and see how Willow's symptoms present over time. And medical research is always advancing. If there isn't a cure in Willow's lifetime, there could be treatment to improve her quality of life.'

I turn to Rory. 'That's our hope – that research and clinical studies might improve her life. We're positive and hopeful.'

'That's a good attitude to have, Pippa.' The doctor's eyes moisten, which catches me by surprise because up until now, I haven't seen a great deal of emotion from her. Marion nods in agreement. Dr Dalia continues, 'I know that it's overwhelming. You didn't expect this.'

I remember when the doctors surrounded my hospital bed in the maternity unit two days after Willow's birth. The trundling sound of the trams outside the room signalled a bustling, ordinary day, only it wasn't "ordinary". Not for us. Rory and I held our breath as we listened to the diagnosis. I had asked if it was caused by something that I ate or something that I did. One of the doctors firmly responded, 'It happened at conception. Not your fault.' The rest of the information washed over me. During that time, Rory was my rock. But when he fell apart two weeks later, I had to be strong for him *and* our daughter.

I massage Willow's hand. 'We were going to name her Kate, you know. But after the diagnosis we decided to call her Willow hoping that as she grows, she will adapt and bend to what life presents to her. We want her to be like a willow tree – majestic and strong.'

Dr Dalia reaches out, touching Willow's lilac blanket. 'She will amaze and surprise you, I'm sure of that. She is so much more than the label of her diagnosis.'

'Is there a support group we can connect with?' Rory asks, his head turning to Dr Dalia and then to Marion.

The doctor sighs, 'As you know, Willow's genetic condition is rare—'

'How rare?' My mother interrupts.

'Quite rare.'

'So, what?' My mother slants her eyes, insistent on knowing the specifics. 'One in a million, one in two million?'

I swallow my boiling anger. Perspiration tingles from the top of my spine down to my lower back. The manilla folder on my lap slips onto the floor and sheets of information from previous discussions with medical staff, fan over the carpet. Rory retrieves the papers while I focus on the yellow walls and try to steady my breathing. Eventually, I turn to face Dr Dalia and Marion. 'We intend to give Willow every opportunity in life, and we'll encourage her to do things her own way. That's what Rory and I believe, right Rore?'

He nods and takes my hand in a show of solidarity. 'Pippa and I have organised a physiotherapist to visit our home and our community health nurse has been unbelievably supportive, hasn't she, Pip?'

I nod in agreement. 'We're doing everything we can to plan ahead. Our paediatrician has also put us in touch with an occupational therapist and a speech therapist.'

Dr Dalia taps at her computer, and we fall silent, running out of words. Marion glances at her wristwatch, then stands up and holds out her business card to Rory. I feel affronted – why she didn't give *me* her details?

'Call me if you need to talk.' She stands away from us, her feet pointed towards the door for a quick exit. Then she backtracks. 'There will be assistance through your local council if you need help with Willow's care.'

'We can manage.' I spit out the words more harshly than I intend. Marion bristles, blinking rapidly, then walks abruptly into the corridor, leaving me to wonder if I've offended her.

We shuffle to the waiting room and settle in to wait for our next appointment. Mum excuses herself, mumbling something about a pedicure appointment. Her perfume lingers long after she's left. No doubt she's glad to be outside, away from the bewildered parents who like us – hanker for that time before, when we were oblivious to what we know now.

My eyes focus on a print on the wall. Memories filter like suspended ghosts through the archives of my mind. The print depicts an old stone building, with a blue bicycle propped up on a wooden fence. Scarlet geraniums seep through an iron gate. The scene takes me back to our holiday on the Isle of Capri. Days of endless sunshine, pebbled beaches and cliff-top cafes.

I'm back with Rory, in Italy – in the hot European summer of last year. We're in a restaurant with Elvis Presley crooning, 'It's Now or Never' in the background. The restaurant is so kitsch, it's almost understated retro. Fishnets hang from the ceiling and faded prints of fishing boats line the walls. The food isn't fancy, just bowls of rustically cooked seafood and pasta. While we eat, aromas tantalise our senses. A fragrant, earthy tomato salsa filters from the underbelly of the kitchen. Little did we know that our daughter was already with us, a kernel of life inside my womb. It's a memory that I pull out, unfold and relive, more so –

lately. The yearning for that time, hits me occasionally, when things get too much. We were carefree with little to anchor us. We had plotted out how long it would take to pay off our mortgage if we both worked part-time for the first year of starting our family. My wage would pay the bills and our living expenses, if we weren't too extravagant, and Rory's wage would cover the mortgage payments. We've got this, we thought, but we didn't factor in having a child with so-called "special needs".

After a day at the hospital, we finally retreat to the sanctuary of our home. We watch Willow's chest rise and fall as she sleeps. My heart swells with love for her. Rory puts his arms around my shoulders. 'Are you going back to your Mother's Group?'

I inwardly shudder. The smug look on their faces when I explained what the doctors had told us about Willow's diagnosis, I knew that they were all thinking, *glad it's you and not me*. And then that horrifying moment when Danielle's four year old son pointed to Willow's nasogastric tube and yelled out, "Yucky". I close my eyes in an attempt to block out the recollection of that day. Shaking my head vigorously, I answer him. 'No, I'm not going back. I want to find a playgroup where Willow can have friends and be supported without judgment. There's too much emphasis on life being perfect in that group. Me and Willow don't fit in.' My voice cracks with emotion.

The next morning, I'm mindlessly watching children's shows on TV. Willow sleeps in my arms and I'm standing in front of the TV gently swaying her from side to side. She spends a great deal of time sleeping, which most parents would relish, but I want her to be alert, to cry, to scream when she feels the pangs of hunger, like most babies do.

The doorbell rings. I open the door with Willow in my arms. My mother-in-law, Janice, has her car parked on the road with the engine running. She points to my feet.

‘There’s a tray of lasagne and a pot of pumpkin soup, there for you and Rory. Is he here?’

She shouts over her shoulder while darting to her car.

‘He had to go to work. Do you want to come inside, Janice?’

Part of her is already in the driver’s seat. ‘Sorry, too much to do. Off to the hairdresser.’

I stand at the door shaking my head, watching her drive away. This has been *her* way of helping, dropping off meals at the door, like a stranger who has no bloodline connection to us. Questions rise like serpents in my head. *Why do family and friends have so much difficulty dealing with this? Why are we made to feel as if we have to apologise for Willow’s condition - like it’s our fault somehow?*

Rory’s way of dealing with his mother’s detachment is by saying ‘She’ll come around. She’ll thaw into the situation.’ His mantra of reassurance. I find it confounding. Willow deserves love like any other human, and Rory and I need support, not attitudes of indifference.

I place Willow back in her cot, then walk back outside to retrieve Janice’s meals. The children’s show ‘Bluey’ is on the TV in the background. I want to sink into a world of fantasy and make-believe, a world filled with promise and happiness and rainbows and sunshine. Not a future of challenges and unknowns.

The doorbell rings again and I wonder if Janice has had time to re-think her attitude towards her granddaughter. I turn off the TV and open the door. My Aunt Meg and Uncle Frank greet me with banana-wide grins. Frank has a massive hamper of baby items in his hands. Meg puts her arms out to me, and I fall into her. ‘Pippa, Congratulations. We came back from our cruise last night and we couldn’t wait to see our grandniece.’

Meg and Frank talk over each other, finishing each other’s sentences and chide each other with genuine warmth. I’m belly laughing already, feeling emotions I haven’t felt for

ages. I make mugs of tea as they ask how Rory, and I are coping and how we're juggling our work commitments. They recall years of fractured sleep when their four adult sons were infants. They pepper our conversation with family gossip, and it feels as if a knot inside of me is untying, because it's a relief to talk about things other than Willow's medical condition.

Meg rolls her sleeves up. 'Now, how can we help?'

'I haven't managed a shower today,' I say.

'Okay, off you go. We'll look after Willow.'

Half an hour later, I'm showered, my hair washed and blow dried and I'm feeling human again. The kitchen is spotlessly tidy, and Meg has brought the washing off the line. Frank is outside mowing the ankle-high front lawn.

Meg smiles at me as she folds sheets. She tilts her head towards the framed photos of Willow that line one of the walls. 'She's beautiful, Pip. Her gorgeous dark hair and her long eyelashes, and your full lips, bits of you and Rory that make her who she is. You should be so proud of her.'

I close my eyes, and my tears start to waterfall without warning. Meg wraps her arms around me and offers tissues from the box on the sofa.

'Oh, Meg, all that people see are Willow's medical issues. They can't see beyond that.'

Meg tightens her arm around me. 'Willow will make her mark on the world in her own way. You'll see.'

I tilt my head on her shoulder and for a few long minutes my world slows, and I feel a calmness I haven't felt since Willow's birth. A cry cuts into the silence. Instinctively fear flows through me. 'Oh hell!' When we stride into her room, Willow has her hands out of her blanket and her fingers are reaching to the moon and star mobile above her cot.

'I've never seen her do that. That's amazing!' I take my phone out of the back pocket of my jeans and snap a photo to send to Rory.

'May I?' Meg asks. I nod and she scoops Willow into her arms.

Willow studies Meg's face and then her blue eyes drift over to me. Her lips open into a smile. Her first smile. I stroke the side of her cheek and she responds by making a cooing sound. Another first. The first of many firsts ... I hope.