FIRST PERSON



BABIES DON'T HAVE STROKES, DO THEY?

While her newborn daughter lay under a tangle of tubes in an intensive care unit, grief-stricken *Flora Watkins* struggled to understand what had happened. This is her heartbreaking account of those early days his morning I held my baby girl for the first time. There would be nothing unusual in this were it not for the fact that I gave birth to Romy nearly three weeks ago. She is the most enchanting child, with sloe eyes, soft skin the texture of a ripe peach, long, elegant fingers and a cap of glossy black hair. She also has a thick plastic tube down her throat in case she forgets to breathe a cappula

throat in case she forgets to breathe, a cannula in her hand the size of one of her fingers and another in her foot. On her chest, sticky pads monitor her heart and respiration, while a feeding tube in her nose is secured to her cheek with a teddy-bear plaster. Until this morning I had only stroked her through the windows of her little incubator. I didn't even see her until she was two days old, wheeled up from the postnatal ward by my husband Nick, with my catheter looped over the armrest.

When I came round from my baby's difficult birth – caesarean section, general anaesthetic, me haemorrhaging on the operating table – she wasn't there. Whisked up to the newborn intensive care unit (NICU) as a precaution, I was told, a 'bit sleepy' from the anaesthetic. We weren't unduly worried – the doctors had warned us this could happen. For now, I was the focus, shaking uncontrollably as I woke up. Then I started to bleed heavily and a midwife hit the crash bleep. Suddenly several doctors surrounded my bed.

It wasn't until a few hours later, once I was stabilised, in a side room off the postnatal ward – away from all the mothers cradling their newborns – that I started asking for my baby. But she never came back. Nick went up to see her and returned with photos of a bonny 8lb girl with a startled expression and a shock of black hair. There was a cannula piercing her hand, thick tubes in each nostril.

I started to cry. 'Romy, Romy...' Just the night before, we'd talked about our favourite name and how we thought that a Romy should be dark, but our baby was sure to be fair like us or auburn like her two brothers. But this baby was definitely a Romy.

'She isn't responding as quickly as they'd like,' Nick said, stroking my hair, trying not to let the worry show. Later, after his next visit, 'They're keeping her in overnight.'

The next morning, I was too sore to heave myself into the wheelchair. Nick was able to give Romy a bottle and brought back videos of our perfect little girl feeding and examining her long fingers intently. I tried not to look at the tubes. I begged the midwives for more morphine so I could get up and go to her. By the time they relented and I made it to her side, frantic by now to hold her, she was sedated. The wires and tubes had multiplied. Tears streamed down my face as I stroked her soft cheek through the porthole of the incubator.

'We think she's having seizures,' said a doctor and Nick had to wheel me away as my sobbing, my howls of disbelief, threatened to disturb the other babies. Back in our room, I began to scream. 'How did this happen? They promised me the anaesthetic wouldn't harm her.'

'I don't know,' Nick said, and we held each other, shaking, before falling into restless sleep.

Later that night, two consultants came to wake us. I screamed as they opened the door, fearing the worst – that we'd lost her. But they had come to tell us they were intubating Romy (inserting a breathing tube) as they'd had to increase the sedation. The seizures were now officially 'worrying'. But they couldn't tell us why they were happening to a child who had been described by the sonographers at two separate scans as 'a perfect baby'.

The following day, an MRI revealed the devastating news that shortly before or during her birth, Romy had suffered a stroke. We couldn't believe what we were hearing. Neither

TEARS FELL AS I FELT HER SOFT CHEEK THROUGH THE PORTHOLE OF THE INCUBATOR'

of us had any idea that newborn babies could have strokes.

A consultant explained, kindly and carefully, that some clots had broken away from my placenta and caused a blockage in Romy's brain. We would probably never know why it happened as most cases of foetal strokes are unexplained. We struggled to take it in. A stroke. Damage to the right side of her brain. Hemiplegia was the term he used – cerebral palsy in layman's terms. Our daughter would have stiffness and weakness on her left side. A 'subset' of these children, he added, have learning difficulties, but it was far too early to tell if Romy would be among them. For now, his concern was stopping the seizures, which were 'at the more severe end'.

Nick and I clung to each other when he'd gone. I felt the lowest, the most wretched that I have ever done. I didn't think it was possible to know a greater grief than after my mother's death when I was 22, and my dysfunctional family fractured. But it was. 'Romy, Romy, Romy!' I cried, over and over again. 'How could this happen? Why did this happen to you?'

When I married Nick, all the unhappiness

seemed to be behind me. We had two wonderful little boys, a beautiful house, a lovely life together. Of course, there had been bumps in the road. I'd suffered bouts of postnatal depression after the births of our sons. So our third child, the daughter I had longed for, was the chance for me to have a happier experience of new motherhood.

All those precious hours I'd planned, snuggling with her while her brothers were at school, making sure I treasured every moment this time – all that was ripped away. It was our own cries, not those of a newborn, that disrupted our nights as our beautiful baby lay heavily sedated in NICU, her poor little brain convulsing with aftershocks from the stroke that had destroyed half her grey matter. We didn't even know if she'd survive the week.

'I'm sorry, I'm sorry,' I sobbed, again and again. Sorry that I couldn't keep Romy safe, sorry that this happened to her while she was inside my body, in what should have been the safest, most nurturing environment there is. Sorry that my need for another baby had brought so much unhappiness into our lives, and so much pain and suffering to an innocent child.

'Don't ever apologise,' my husband said to me. 'Whatever happens, Romy is here and she is wonderful.'

But amid this all-consuming grief, an even stronger emotion burned: the fiercest love and pride in my baby. I would hear the word 'fighter' used countless times to describe Romy over the coming days. I would fight for her, too – be the fiercest lioness mama for my darling disabled daughter. She wouldn't just pull through, she would thrive and go on to confound the doctors' expectations.

So the next morning I dragged myself up to the neonatal ward, despite the pain from my scar, and Nick and I entered the netherworld of NICU parents. We sat pressed up against Romy's incubator for hours, the cacophony of clanks, whirs and bleeps from alarms, so deafening at first, gradually fading into the background.

Most of Romy's room-mates were premature babies, tiny scraps of humanity. Beneath the heat lamps, you could almost see these precious hothouse flowers growing, little limbs and digits lengthening and unfurling. Beside them, Romy looked like Gulliver among the Lilliputians. I smiled for the first time since her birth when her nurse called her 'Big Girl' as she took her temperature. I couldn't feed her myself (sustenance came from a glucose drip) or change her nappy, just stroke her through the porthole, say 'I love you' and sing lullabies. Despite the deep sedation, Romy's eyes would twitch. The next day, she curled her fingers around one of mine and clung on tightly. It was her left hand - the one affected by the stroke.

But there were setbacks, too. The dosage of powerful drugs fell and rose again, as the $\,\to\,$

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seizures returned. A different consultant looked at the MRI scan and concluded there was 'extensive damage' to the left side of Romy's brain as well. They bundled me into a meeting room after that, where my sobs wouldn't distress the other parents.

After I was discharged from hospital, our days settled into a strange new routine. The hours spent beside Romy's incubator bookended by the school run. Home for tea, bath and bed, doing my best to be cheerful for the boys. Only when they were asleep would I let myself cry. I'd go into Romy's bedroom, touch the pretty things I'd bought for her – the tutu, the plush bunny – then lie down in tears beside her empty cot.

Then came the day that Romy opened her eyes. She looked with interest from Nick to me, registering the voices she knew. And then my first cuddle. Romy had been twitching and fretting in her incubator. But as soon as the nurse laid her on my chest, she became calm. We lay there, communing and comforting each other, for several hours. 'It was magical,' Nick told me. 'You could see all your worries melting away.'

Now she is more wakeful, and the breathing tube is out, we are having to teach her to suck again. Firstly with 'dummy dips' in milk. But at her last feed, my clever baby managed to take 15ml from a bottle.

'Come on, Big Girl,' says her nurse, 'you're doing well.' This afternoon, 17 days in, Romy graduated from NICU to the high dependency unit, from her incubator to an open cot. She looks at me so intently, so thoughtfully, reaches out with both arms for her Sophie the Giraffe toy her brothers placed in her cot, that it's hard to believe there is anything wrong with her.

We seek out the most positive neurologist, the one who tells us, 'Look at her, not at the scans.' We devour books on the plasticity of infant brains, listen eagerly to stories of fetal stroke survivors whose brains 'rewired' themselves, of children with cerebral palsy who live normal, active, happy lives. And it is this hope, plus the hundreds of acts of kindness from friends, acquaintances – even complete strangers – that keep us going.

We've had help with school runs and dog walking. There have been play dates, presents and parties for the boys and so much food for the freezer that I won't need to cook until the New Year. Prayers have been said for Romy and candles lit at mass.

Under one of my Facebook photos of Romy, the Paralympic equestrian gold medallist Natasha Baker described her as 'absolutely beautiful, special – maybe even a future team-mate!'. And a woman I don't know but to whom I will be forever thankful posted these lines from a Mary Oliver poem on my Instagram page: 'I want to believe that the imperfections are nothing – that the light is everything.'

And when I look into Romy's deep blue eyes,







so alert, so full of radiance and intelligence, her father and I could not believe anything

else. The light is everything.

AT 18 DAYS

ROMY HAD

TO BE FED

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Almost a month after her traumatic birth, Romy came home to her family. Apart from the twice-daily medication to control the seizures, she is like any other baby, feeding and sleeping well, enjoying cuddles and protesting vocally if I'm late with a feed. It will be several months before the effects of the stroke start to become apparent. But the amazing progress Romy has made gives us such hope. She really is turning towards the light.

Follow Flora and Romy's journey on Instagram at @florawriting

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