

Living with Cali

A BLOG FROM A TRISOMY MOM ABOUT LIVING WITH TRISOMY 18
BY 'JAY'



PART 2 — THE FIRST YEAR

When I look back on the early days with Cali, I think how brave, bemused and innocent we both were; brand new parents with a baby who had a variety of complex medical conditions we knew nothing about, sent home from hospital for “family time” by a consultant that thought resuscitation was inappropriate for children like ours. As I write this, 3 ¾ years have passed since then, and though I still think that we must continue being brave, and I certainly spend a lot of time feeling bemused, I no longer feel innocent, that disappeared quickly. It was a rapid learning curve and between the daily sobs, the endless expressing of milk, the cuddles, the cake, the cards and the afternoon naps from which we would awake desolate, I did what many other mothers in my situation do. I learnt everything I could about my daughter's condition so that I could try and gain a little control and perhaps make things better.



I discovered that there was a Facebook group of mainly American mothers. I read endless posts on all the hundreds of issues that children with Edwards Syndrome can present with, absorbing anything that felt relevant and chipping in if I had anything to say or ask. I realised, in America at least, there were a lot of children that had survived the first year, though they all seemed to have incredibly complex medical needs. Meanwhile C took time off work, listened to my new knowledge, doted on Cali and nodded off holding her. From his science days he taught me how to use the syringes properly and sat up next to me in bed in the early hours pouring milk into Cali whilst my breasts were mechanically masticated by “Pumpy” the huge breast pump we'd hired in order to extract as much milk as possible from me.

In amongst the chaos of emotions was Cali, our girl. A solemn little thing that slept and slept and who didn't actually have the apnoea's or the aspiration pneumonia or the heart failure we'd been expecting. She'd wake for a while and regard the world gravely, but I fancy with some of the humour we know so well now. She very slowly grew out of preemie clothing and started to wear new-born clothes. Every week women in purple turned up to give us "respite". I didn't understand it at that point, respite from what? I had no clue what to do with these hours. I'd lie upstairs alone with my numb, exhausted thoughts, whilst downstairs the kind, cheerful women bedecked Cali in fairy lights and lay her on a crinkly silver emergency blanket. They were desolate times but also intensely happy times too. In amongst all the strangeness of this new world we would laugh as we fell in love with the funny ways of our baby and we would read to each other as we lay in bed taking it in turns to hold Cali. C's mum left after a month and we started caring for Cali alone. Like any other couple we rowed and hated each other and cried and loved each other as we did our version of becoming a family.

About 10 weeks in Cali started doing something strange. She would fall asleep and then immediately wake up, over and over. It was very distressing, especially as she was worse when she was held. Painful hours passed lying next to her watching her endlessly awoken with a little noise at the back of her throat. I imitated the noise until I thought I understood it. I asked the American mums what they thought, I even asked my NCT group if their babies did it, hoping it might be normal, only one person responded. I decided that Cali had obstructive sleep apnoea and something in her airway was blocking off as she went to sleep. It took three awful weeks before we saw a respiratory consultant who confirmed this diagnosis and thankfully had the same solution in mind that I'd read about. This consultant was the first professional who was interested in treating Cali rather than seeing her as a palliative care case. We were both a bit in love with him by the end of the appointment.



Just before the meeting Cali's neonatologist turned up, he'd come specially to the hospital to tell us not to let things get too medical. We weren't sure how to decipher this. Some months later I met him in the street and he told me his attitude towards Edwards had changed because of Cali, but at the time I think all he could see was his fears that against Cali's best interests we would refuse to let her die and pursue any medical solution. I hope he still doesn't have a blanket policy of saying that any type of resuscitation is inappropriate for children with Edwards Syndrome.

Cali's floppy airway was greatly improved by her wearing a short tube in her nose (a Nasal Pharyngeal Airway or NPA) which kept the airway open. A miracle! She started sleeping and putting on more weight. Now we had to learn how to put the thing in ourselves, how to suction, how to sew the damn tubes together (C's special skill) and attach them to her face. We also had to start carrying a huge, heavy suction machine around with us in a subtle shade of bright yellow.

At this point enter Penny, whose then 3-year-old daughter Amy with Edwards also wore an NPA. Since our meeting on Facebook, Penny, who I have still only met once, has been the most incredible support through every single illness and perplexity we've ever had with Cali. She sends long, patient messages full of humour, never complaining about her own difficult circumstances and always full of gentle suggestions and ideas. Life immediately got less lonely once I met Penny. When at 6 months Cali had her first serious admission with bronchiolitis and we were told they weren't sure if she would make it, she told me that Cali would be fine, and I drank up her words, able to believe it from her. And she was right. If you have one friend walking the same path as you then it's enough, and these days I have quite a few of these friends.

Just before we went into hospital to have the NPA tube fitted Cali smiled for the first time. Good timing Cali! That smile, even though later we realised it was at the patterned pillow case behind us rather than at us, gave us what we needed at that point. That smile in fact is the thing that keeps us hopeful and loving through all the hardship that caring for this very complex little girl has brought. There is always a point after a prolonged illness in hospital when she smiles again, and it feels like the sun breaking out from behind a cloud, it lifts me out of my numb state where I am unable to feel too much about the skinny, spaced out creature in the hospital bed, onto a wave of love as I see my lovely daughter checking back into our world.



So, time passes, and we get more adept at understanding Cali. C returns to work. Life is still harrowing, especially when winter arrives, and we realise how a simple cold can turn into a hospital admission. Arrangements are often cancelled because somebody feels a bit snotty, I would even flee with Cali from shops if I heard somebody coughing. But we managed Cali's first Christmas at home and not that long after was her first birthday. With her birthday it felt like a curse had been lifted, everybody knows the statistics for a baby with Edwards surviving their first year, but nobody has a clue what to say when this happens. We were sailing free and faced with the unbelievable possibility that Cali was one of those children that would survive longer.

Jay