

# Our Altered Life by Charlene Beswick

## Chapter One

### **Something is wrong**

“Your son has been born with half a face.”

Okay, so that’s not exactly what the consultant said, but it’s basically what it boiled down to.

I had undergone an emergency caesarean a couple of hours earlier and had delivered twin boys. I had assumed that they were healthy. Why wouldn’t they be? I don’t smoke, hadn’t drunk alcohol, ate well and never, not once, did I think I’d have anything other than two perfectly formed, healthy children. But now I was being told otherwise.

Mark, my partner, was sitting to my left having just come back from making all the customary phone calls to announce the safe arrival of two boys. The midwife had popped her head into my cubicle while he had been gone and said that she’d come back when Mark was with me. I remember that her smile made me feel uneasy for a moment, but it passed as quickly as it came. I was still ‘fuzzy’ from the drugs and very tired, and so I dismissed my brief concern.

Once Mark was with me, the consultant came and sat at the foot of the bed, and Sarah, a lovely midwife about the same age as me, sat next to him, to my right. I remember being aware that she was watching me intently. Now I know why.

The consultant, Dr Mona, explained that twin one (Oliver) was fine, but twin two (Harry) had some problems. I can still see the way that Dr Mona drew an imaginary line down the centre of his face with his hand and swept it across to the left side as if he were erasing what was there. I processed it all in painfully slow motion, as if I were dreaming. His voice was muffled as if he was talking to me underwater. I could hear the odd word, dulled by my delayed understanding and the pounding in my ears. At the same time, he was mentioning something about no eye, a small, under-developed

ear, no nostril, a short and slanted jaw. He mentioned Golden something syndrome and hemi something or other. I now know these to be Goldenhar syndrome and Hemifacial Microsomia – different terms for similar conditions. Associated with this condition are heart defects, spinal problems and brain damage, but it was too early to know how severely Harry had been affected. He'd also been born with only one artery in his umbilical cord instead of two and the implications of this were, again, unknown at that time.

*Dream. Bad dream. Thick, thick fog. What?*

I remember looking from Dr Mona to Mark repeatedly as he told us the news like a person would look to a translator for help understanding a foreign language. I couldn't process this information. Not us. Not me. No. I felt as though I was drowning. This wasn't what was supposed to happen. Parents were told the weight of their babies. That it was time to hold and cuddle them. To gaze into their little eyes and pour themselves into their perfect creation feeling – an elation beyond anything they had ever known. It must be a mistake.

I sat perfectly still, frozen in that moment that I would relive for years to come. All I could whisper as fat, slow tears rolled down my face was, "I'm sorry. I'm sorry." No hysterical outbursts or sobbing convulsions. Just a paralysis of disbelief and guilt.

Despite being shocked and stunned, I found the guilt overwhelming. Mark squeezed my hand and told me I had nothing to be sorry for. Dr Mona also assured me that it wasn't due to anything that I had or hadn't done throughout the pregnancy, but I couldn't think anything else. When did it all go wrong?

*Think, Charlene. Think. What did you do? What have you done to your child?*

Hot on the tail of guilt came a much darker emotion. Fear. Dr Mona sat in front of me, describing a baby who only had half a face and, for all we knew, no quality of life ahead of him, and yet I was expected to love him. But what if I couldn't? What if I couldn't look at him, let alone hold him or bond with him? What if I was repulsed by this strange looking baby that I'd not expected or prepared for? Surely everyone would know just by looking at me, I wasn't the mother this boy needed.

When Sarah asked if I wanted to see him, I was absolutely terrified. Seeing him was the last thing that I wanted to do at that moment, but I said yes. What else could I say? What sort of cold, hard, unfeeling, wicked (feel free to add your own adjectives) person would I have been to admit my fears to anyone? It's only now when I reflect on those moments that I realise they were perfectly normal.

By now I had called the one person who I felt had the magical power to make this all right for me, to hold me through my nightmare and shush it all away. I don't remember what I said to my mum on my phone in the hospital bed. I know that I whispered, partly because only a thin curtain separated us from a ward full of mothers I no longer had anything in common with, partly because I knew that the alternative to whispering would drain me of any bit of energy I now had left. I think I said, "Something is wrong," and I cried. Mum left work immediately to come to us.

Many years later, when I faced all these feelings in the safe space of a therapeutic setting, I pictured a vase. Beautiful, big and colourful, but it had been smashed into hundreds of pieces. Every fragment had been retrieved and painstakingly reassembled so to all the world it still looked like the proud vase it once was. It still did the same job, but it was a fragile version of its former self. Changed for ever. That moment, that day, was when my vase tipped off the edge of its table, hit the floor and shattered.

I don't know how long it was before the wheelchair came to take me to the Special Care Baby Unit (SCBU). The excitement that had filled me less than 24 hours ago felt like someone else's now, and all I had left was fear, dread and a sickness in the pit of my stomach. I forced a smile and got in the wheelchair. It was time to meet my boys.