

Michael's Story

In 1990, I was a parent of three children, aged 3, 10 and 12 years — all girls. During the year, after 14 years of marriage, my husband and I separated. It was just a week before Christmas. A little more than a week after separating from my husband, I found out I was having our fourth child. Despite my husband's suggestions (I had absolutely no interest in reconciling with him), I decided to go ahead with the pregnancy. After all, I already had three — four should not make all that much difference, I thought.

I needed to take desperate measures to ensure our financial independence as a family so I decided to undergo a six week full-time secretarial refresher course, learn how to use computers, improve my keyboarding speed and update many other aspects of my office work skills. I placed my youngest daughter into a child care centre while I did the course. The course commenced when I was 28 weeks pregnant, and was successfully concluded when 34 weeks pregnant. Planning ahead, I decided to book my unborn child into a child care centre with my three year old daughter. The grand plan was that I would enter the work force after a 14 year absence when the baby was three months' old. So, I thought, there would be nothing to worry about, no financial problems, I would be able to keep my home and mortgage, and all would be sweet.

How wrong I was! At least in the beginning it seemed I was wrong. I decided not to have amniocentesis as I had experienced two miscarriages and I was aware that this process could initiate another. In addition, I had no interest in aborting a foetus for health reasons. So I continued on.

When my son was born I was so jubilant. After three girls, I had a much-wanted son. The attending midwife said to me however, ... 'he looks like he has Down Syndrome, did all your children look like that?' During the birth, one of my arteries was severed so I was haemorrhaging profusely at the time. There were two other midwives present and one told the other to locate a doctor quickly. I was losing blood at an alarming rate which I was not aware of at the time.

The attending midwife was stuffing everything inside of me to stop the bleeding — towels, sheets, anything she could find. The pain was excruciating, like someone had set me on fire. The burn was intolerable. When the second midwife came back without a doctor, she said ... 'I did not wake him because he is asleep.' The attending midwife then demanded that she wake the doctor up to attend immediately.

The doctor attended to me and as he was stitching me up for what seemed forever, I asked him about my son. Did he think my son was disabled? Did he have Down Syndrome? The doctor did not comment. He was too busy piecing me together. I was not only in pain because of the severed artery and the process that was happening to rectify it, I was beside myself with worry about the condition of my new son.

My son, however, was very quiet. The Apgar scores showed a 9 out of 10 result so no immediate concerns were apparent for him. I, however, noticed there was something wrong. He was not having a bowel motion and all he did was sleep all the time. He would not feed either. Later I was transferred to a ward and reported my concerns to a registered nurse. She told me I was probably not feeding him properly, even after my experience of having given birth to three other children!

She commenced to bottle feed my son, but she too, was unsuccessful. My concerns were then relayed to the paediatrician. The paediatrician diagnosed Hirschsprung's Disease. Hirschsprung's

Disease affects different parts of the bowel, but in Michael's case, he had no nerve cells in his bowel, meaning he could not have a bowel motion. The doctor went on to explain that because he has Hirschsprung's Disease, he is more likely to have Down Syndrome, and there may be a possibility of a cardiac problem. His abdomen was continually expanding and he was in pain.

Michael had to be transferred to a specialist children's hospital for immediate surgery. As I saw my three day old son being taken away I thought I would never see him alive again. I was not sure how I would survive through all of this but I had no choice but to try my best and do whatever it was that I needed to do.

Michael, however, had plans. He was determined to survive, and more. He now had a colostomy bag so care of the bag was the first skill I learned. He did have a cardiac condition — Patent Ductus Arteriosus (PDA) and a Ventricular Septal Defect (VSD). The PDA was a hole that eventually closed, but the VSD never will. As a result of all the complications, including the Down Syndrome, Michael was to be intensely monitored by his paediatrician for the first five years of his life. This meant many medical appointments each week, early intervention with physiotherapy, speech therapy, occupational therapy, stomal therapy, and an endless round of specialists.

In conjunction with all the medical intervention and appointments, Michael had many admissions to hospital, both related and unrelated to his disabilities. His visits averaged one every two months for about five years. Each stay averaged from about 3 days to about a week.

In the meantime, I had to care for my other three children with very little support from the children's father. My own family did whatever they could to support me. The thought remained with me though, if we were to survive as a family I could not lose sight of my personal development and career aspirations.

Michael was now two years old and I decided I had to do something drastic. I became a volunteer Lifeline telephone counsellor and was accepted into university as a Bachelor of Arts student. I still had to find work so I found employment as a worker in the community doing case management as a family support worker.

So commenced the all-consuming juggle of home, hospitals, children, work, study and volunteer work. During this long and exhausting process, I gained my degree, raised my children, worked part-time then full-time, and cared for my son.

The struggle for survival has been long, hard, difficult, sometimes fun, sometimes interesting, and certainly a learning experience not only for myself but for my family as well. So far we have survived, with a lot of hard work and determination. My three daughters all work as carers of children, adolescents and frail aged with disabilities. They are so skilled that their expertise in the field is in demand. All three girls have successfully undertaken tertiary studies as well.

Michael is now fourteen years old and has overcome much of the health related complications he was born with. He attends a special school and has achieved much in his life.

My message with this story is that initially Michael's disabilities and care looked to me to be an impossible task. I could see no future for all of us. All I could see was a black future with nothing ahead but hardship. My perspective on this experience has now changed. As a family, we have not only survived, but have had many achievements, and learned much from our teacher, Michael. We have endured hardship and took the hard road, some would say I could have had an

abortion and prevented all this. I say that I would have lost not only a child in the process, but all the experiences, the people I have met, the friends I have made, the studies I have completed and the skills learned. This would not have happened if I did not have my child with a disability. My life would have taken a vastly different path, not necessarily a better one.

Carmel Flavell

Note: Since writing this story, Michael's father was killed on 20 January 2006. He was driving a semi-trailer loaded with 24 tonnes of steel at 100 k's per hour, had a heart attack and veered off the road and collided with 8 trees. He was killed on impact, leaving Michael and his three older sisters.