

# The power of 13

## A fragile life opens a new dimension to family love

Some months ago one of my daughters-in-law, Tania, announced at the dinner table that she was expecting again, but with a tone that caused me to look up, then to my son, and back and forth. Something was not right. "There is something wrong. They say he has trisomy 13. Do you know much about that?" I am a paediatrician who has specialised in care of very sick babies. I know a lot about trisomies, but how to share that knowledge? With tears, I am afraid.

Trisomy 13 means there are three copies of the 13th largest chromosome in every cell of the body. There should only be two copies. The extra information delivered by the third copy interferes with the development of the baby, particularly the brain. But the face, the heart, the limbs and fingers — almost everything — will be abnormal, and life will be restricted to hours if the baby is born alive. Chromosome 13 is bigger than chromosome 21, whose trisomy results in Down syndrome. The greater the amount of genetic misinformation, the greater the disability. Babies with trisomy 13 are, therefore, much more disabled than those with trisomy 21.

In Tania's case the diagnosis was made at around 14 weeks of gestation, after it had been suggested by ultrasound abnormalities and confirmed by amniocentesis. In all my 40 years of caring for sick children I had never observed a mother who had not elected to terminate a pregnancy affected by trisomy 13, and I awaited the inevitable statement. I imagined (but what male can know) something of the pressures on her. I had observed mothers struggling with grief, misplaced guilt and the questions of whether it would be unfair to continue the pregnancy. What would its effect be on her five other children, on her relationship with the father, on herself? There was silence in the dining room which seemed to go on for ever. My opinion was awaited. Lord God, what do I say next? What do I do now?

But Tania had no intention of terminating the pregnancy. She carried to term, held the boy, Mitchell Darcy, for 18 and a half hours until he died, and took 4 days to be able to leave him behind and go home from the hospital. She continued to weep but gathered strength to go on to deliver a eulogy beside the little white casket at the funeral several days later. Before a congregation stilled with emotion, she articulated something of what we had sensed during the pregnancy — something new, something wondrous though painful. As if turning a gem to reflect yet more displays of colour, she confirmed a new dimension to a mother's love, brought a new dimension to family life and, for me, as a Christian, a fresh dimension of the value of imperfect, transient life. Perhaps He really does care about the fallen sparrows?

While Tania never seriously considered termination, she confessed in the eulogy to have felt "numbness,

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terror, pain, deep confusion and heartache all at the same time" after being told the diagnosis. She decided she would give the baby as much life, as much of her love, and as much family fellowship as she could muster. She declared to the child at the funeral, "I tried to give you a life inside me. I ate lots of ice cream, so you could taste it. I sat in the sun, so you could feel the warmth of the rays. I religiously took my vitamins, to help you grow. I sang to you. I talked to you. I talked with you and told you stories about your family. I explained that all that noise was your big brothers and sister, who were so excited about your arrival. I used to lie in bed and cuddle Daddy, knowing that you were in the middle being touched by us both.

"As the day of your birth grew nearer, I was torn. I wanted to meet you, to hold you in my arms and kiss you all over. But the knowledge your birth would create problems for you, that it would be the start of your having to breathe on your own and sustain yourself, tore me to pieces."

The child was born alive in April 2013 by elective caesarean section because of previous similar deliveries. Tania was conscious. The father was present. The baby was limp and blue but breathed, and was able to be introduced to his family.

Tania eulogised, "There was so much love in the [delivery] room. I had the privilege of holding you on my skin for 18 and a half hours. Thank you for trying your hardest to stay with us. I hope you felt and knew, while you grew inside me, and when you were born and with us, that you were and still are loved as unconditionally, as completely, and as fiercely in that short time as anyone could hope to be loved in a lifetime. One moment you were in my arms ... I was holding your hand, and then in a heartbeat you were in the hands of God. I pray that when I walk through death's portal, Mitchell Darcy Whitehall will be the first face that I shall see, running towards me with your arms spread wide saying, 'Look, Mummy is home'".

The other children, four boys from 3 to 8 years and a little girl aged 2 had all been "in" on the pregnancy. They had chosen the child's name. They had counted the weeks. They had felt the baby moving and observed its growth. Of course, they did not understand but were informed Mitchell would not be staying with us for long: he would be going "home" because he was not really made for this world. There was, however, a painful side to this because they had observed a Grandma going home not long before, and she had been part of their lives. How can you explain these things to children?

Somehow, they seemed to comprehend and when the day of the funeral arrived, with solemnity and with not one punch or poke, they dressed in their new clothes, went to the car, filed into the church and proceeded to the front. For small boys used to chasing footballs, they were an intuitive "honour guard" for their brother, however it cannot be said that the 2-year-old girl departed from her usual gay and exploratory self.

Mercifully, she skipped from soul to soul, from row to row, warming hearts in her wake.

During all this my son maintained his usual silence on intensely personal matters, and it was hard to know what he was thinking. He had had the job of driving in to the hospital to bring Mitchell out to the funeral parlour and there had been concern about how long it was taking. Much later I learned he had taken the boy to visit the island and little beach at La Perouse where the child's siblings loved to play.

As the family is living with us, my wife and I had also been drawn in to the saga. I was invited to translate various reports and comment on any "progress" of which, of course, there was none in the physical world. Once (why only once?) we prayed together around the dinner table.

As Tania was to have a caesarean and our son would be with her, my wife and I were to take turns minding the children in the hospital, so they could meet Mitchell as soon as possible after delivery. We all got up at about 5.00 am to travel into Sydney, as Tania was allegedly first on the list but, inevitably, she slid down to an afternoon operation. In the meantime, I took turns walking the children up and down the long corridors.

In the foyer a stall had been erected and "pink lady" volunteers were selling toys and stuffed animals. This spectacle inspired a buying frenzy in my charges and, at that stage, I was prepared to part with any amount of money for a bit of peace. It dawned on me, however, that the frenzy had developed a kind of cerebral edge: there was discussion, selection, reselection and no argument. I noticed each selection was different: a different animal, a different colour. The 3-year-old settled on a stuffed



caterpillar, as long as him, as thick as his leg, segmented brightly with all the colours of the rainbow, and adorned with bright buttons for eyes and a wide stitched, slightly skewed grin. "Do you really want that, Gus?" I enquired. "It is not for me", he explained, perhaps defensively, "It's for Mitchell". As if by some common inner compulsion, they had all, without prior discussion, rushed for gifts for the unborn. I was astonished. More was to come.

When Mitchell was born and Mum was ready, we were all introduced, one by one, to the new family member. Those who were bearing gifts waited patiently in line. For Gus, the line thing is not popular. But he waited, silently, in turn, then proffered his caterpillar version of gold, frankincense and myrrh. I was shaken and had nothing to offer but a grandfather's sorrow.

A couple of nights later, I was minding all the children for some reason on my own. I heard sobbing in the night. It was an older boy sobbing for his now dead brother. I prayed with him. The little girl woke. More tears. Everyone was upset. I could not leave the children's room (they sleep in bunks) and there was no room in a child's bunk for an extra grandfather and small girl. So I found a blanket and slept on the floor, near the boys with the girl on my arm, thanking Him in awe of the power of love.

In my speech at the funeral, I was able to thank Tania for what she had brought to us all: new insights into the value of life, into the contributions that can be made to the Kingdom in a mere 18 and a half hours of breathing, into a new dimension of family love based on a suffering Son. What a privilege Mitchell Darcy has been. He might have ended many months before as relatively unnoticed (by all but his parents?), like many other imperfect sparrows. Instead, he really did become "of greater value".

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