

A Survivor's Hope.

As a multiple birth loss parent I was determined to make a difference in the way other multiple birth loss families were treated by health care professionals, friends, family, as well as the wider community. It was appalling to think that in my own situation, which had occurred in 1990, that giving birth to both a living and a deceased child could evoke so much fear, ignorance and at times, contempt by those around me. However, it was far more appalling to hear that such behaviour had not changed in over a decade since I had experienced my own loss, when a case came to my attention in 2001.

To hear news from a bereavement care colleague about a South Australian health care professional who had treated the family of twins, where one had lived and the other had died, like it had almost been a personal inconvenience in time and paperwork was most devastating indeed. It was bad enough to hear of how poorly the health care professional had handled the deceased child's body, let alone the fact that there was an initial refusal to complete paperwork that was required to be done by law. However, when I heard that the deceased child's body had gone 'missing' for the best part of twenty four hours, being shunted around one of Australia's capital cities like a forgotten postal delivery, such immoral behaviour became the spark that ignited my determination to do something to try and fix an extremely broken link in our health care system.

Here was a situation where a mother had given birth to twins. As in my own pregnancy, the mother was aware that one of her babies had died, and had to continue with the pregnancy for as long as possible in order to give the surviving child a better chance at birth. Although this sounds extremely cruel to make a mother endure that type of experience, there is no easy answer to any part of multiple pregnancy loss. You just have to cope with what gets thrown at you, and pray that you get through.

When the little boy who had died was delivered, his body remained intact in its membrane. Normally, if this has not broken, a medical professional carefully removes it. Unfortunately in this instance, the medical professional did not feel the need to do so, and literally just 'plonked' the deceased child's body, membrane and all into a nearby plastic bucket, on which a lid was hurriedly fixed. All this occurred within full view of the extremely upset and traumatised mother.

After the birth, the health care professional refused to complete the required paperwork to register a stillbirth. Staff on duty who were quick to remind this particular practitioner of his legal, and even moral obligations, seemed to achieve the correct response, and the paperwork was filled out.

What was astounding in this particular case was that shortly thereafter, the little boy's remains went missing for the best part of twenty-four to forty-eight hours. Apparently the remains, still inside the plastic bucket, had been transported back and forth across this particular Australian capital city as health care professionals tried to decide what to do with the body.

Eventually, the remains were found by a person who demonstrated enough care and empathy to give the little boy back some of the respect that should have been shown to him from the moment he was delivered. If this had occurred to an older child, or an adult, I am sure that the story would have been plastered across news headlines right around the world. However, in this particular situation, in such a small and seemingly insignificant place, no one seemed to take much notice at all, and the occasion passed without so much as the battering of an eyelid.

Needless to say, the story made my emotions boil over in anger and disgust! I was mortified that such an uncaring approach to anybody's death, let alone a small innocent baby's, could occur in modern times. It drove home the fact that nothing had changed since 1990 when health care professionals had looked at me like I had the plague, and treated me like I was carrying a contagious disease instead of a deceased child.

If I had let the moment go, I would have been as guilty as the rest of them. How could I continue to work in the area of multiple birth loss and not do anything to try and fix such a problem that was one of the most 'unfixable' dilemmas I had ever experienced?

Within days I had called together several close bereavement care colleagues, one in New South Wales, one in South Australia and the other in Canada. This was the beginning of a small change that would hopefully kick start the fight to improve multiple birth loss care. This was our first major project, carried out in conjunction with a large Australian Community Service organisation which was prepared to fund us. The initiation of the "Apex Australia Twin Loss Awareness Kit" saw the next four years of my life rapidly disappear into a sea of paperwork, conflict, negotiation, tears and lots of satisfying pats on the back.

Has the hard work been worth all the effort? Well, when I look at my own surviving twin son, who is now a successful, positive and hardworking young man, there is no doubt in my mind whatsoever. Has my son suffered as the result of being my 'guinea-pig' for years as I studied, observed and carefully noted his emotional and physical behaviour? Not in the least; and just to make sure, I asked him a series of 'interview' questions shortly after his eighteenth birthday, the answers of which were published on a United States multiple birth website.

So much as been documented about the psychological effects upon twins and other higher order multiples who have been parted from their siblings at birth, or shortly thereafter. Most is frightening to read because it reveals a dark side as to how this separation can affect those who survive. Problems such as not understanding why they feel 'different', trying to maintain long term relationships, and looking for answers at the bottom of bottles, in the taking of pills and the injecting of needles has only served to deepen the despair that many surviving multiple birth individuals feel.

Having said that, I was certain that there was some form of hope for these survivors. However naively I was in holding these thoughts, I was sure that a positive side was yet to be revealed. How could we give the parents who were still experiencing the early days and years of their loss any hope if we didn't try and find it for them?

My son became a key to this brighter side. The experiment of trying to be honest, supportive and positive about his twinship had begun to show results and by sharing them with other multiple birth loss parents, as well as health care professionals, gave the work I was doing in multiple birth loss a reinvigorated energy.

Although my own experiences are just those of one family, my research over the years has revealed that I am not alone. Many families right around the world all seek to find a positive side to this problem. We seem to be the ones teaching the health care professionals, the ones who are prepared to stand up and speak for the rights of those who cannot speak for themselves.

When asked as to his thoughts about being a twin, my son was at first, not too sure what to say. However, after dwelling on the topic for a few moments he told me that he was happy in life because he didn't feel alone. He always felt his sister was there with him and that he was a unique person in being a surviving twin. His final comment left me with glistening eyes and I will leave you to ponder it: “I live life for the both of us – and that's a good thing!” I hope you think so too.