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# Twin to Twin Transfusion Syndrome: A Patient's Perspective

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## Background

My husband, Pete, and I are the proud parents of three beautiful children, Charlotte, Max and Oliver. In January 2002 our family was eagerly awaiting the birth of our second child. I was on summer holiday leave from my employment as a physiotherapist working with children with developmental disabilities. Our daughter, Charlotte had been born a little over 2 years earlier. Her birth had been by emergency caesarean section for “fetal distress”. This current pregnancy had been long planned for and after much research we had chosen an independent midwife as our care provider. We were planning a vaginal birth, and were in the midst of planning for a homebirth. Having come from a Western Medical Model health background, this was a big shift in thinking for Pete and me.

Our plans were thrown into disarray by the diagnosis at 19 weeks gestation of twin–twin transfusion syndrome (TTTS). However, all the months of planning were not in vain. I believe the courage to question and analyze what we were being told, and the belief in ourselves that we had gained in deciding to step outside of the square of “normal” birth practices in our society, gave us strength as we journeyed through the painful and heart wrenching weeks and months following our boys’ diagnosis. Our perspective of TTTS is a view from the other side. We hope that it will bring light and knowledge to health professionals who come into contact with people just like us.

## Our Story

January 23, 2002 was the day my family’s life was turned upside down forever.

At 19 weeks’ gestation I was very big. Twin jibes had started early. At my 16-week checkup with my independent midwife I was slightly bigger for dates, but no second heartbeat was detected. We had discussed twins as my mother had relayed a dream to us in which I was pushing a twin pram. She was known to have had these “premonition” type dreams in the past. Annie — our midwife — palpated my stomach carefully — it appeared to be just one baby. Over the next 3 weeks I ballooned. I was in telephone contact with Annie, telling her of my increasing discomfort, but I just kept putting it down to being my second pregnancy. I reassured myself that the ultrasound was soon, and then all would be revealed. By the time I was checking in for my ultrasound at 19 weeks’ I was getting many questioning looks. I was the size of a full term pregnant woman and felt very uncomfortable

When the ultrasonographer pointed out two babies within a few seconds of beginning the ultrasound, my heart jumped but it only confirmed what I already knew deep in my soul. Overwhelming tears followed — how was I going to cope with a toddler and two babies? But something was not right and my mothering instinct sensed it almost immediately. Twin one was swimming in a huge pool of fluid. Twin two was smaller.

I had heard of TTTS, although I wasn’t sure what it was — I had worked with the severely disabled survivors in two different cases in my profession as a pediatric physiotherapist. I offered this information to the sonographer — she only commented that all the babies’ structures were present and normal. A second opinion was sought immediately from the Chief Ultrasonologist and we were asked to sit in a private room. Having worked in the health field I knew that this was not a good sign! Bad news was pending. In an honest and frank way we were given the news: severe TTTS. The prognosis was presented — our twin boys were in significant danger of premature birth, death or disability.

Our plans and preparations for a homebirth with our independent midwife were thrown into disarray. As a proponent of minimal intervention in normal pregnancy and birth, I was generally distrusting of the obstetric profession. Suddenly this pregnancy was no longer normal and I needed an obstetrician. I needed to see someone who knew about TTTS, and importantly respected my opinions and wishes. We were given a name and after telephone calls to Annie and my family doctor we fronted up to the Obstetrician’s private office unannounced, without a referral and in fairly desperate need of some quick attention. Within hours we were sitting in his office and spent over an hour on that first day with him. It was important that we make some rather difficult decisions quickly as premature labor was predicted to be imminent.

We were given all the facts, with medical literature and websites to review. We were told that we had a 33% chance of bringing both boys home, and a 60% chance of getting one of the boys home. Firstly though I needed to have an amnioreduction to prevent the onset of labour in the coming days. This allowed us a little more time to make the hard decision about ongoing management of the pregnancy.

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In our minds we had to give both of our boys every chance and we made this clear to our obstetrician. Therefore, amnioreduction and laser surgery were the only two options that we were prepared to consider.

We sat down with all the facts as they had been presented to us and drew up a list — pros and cons for the two options we were considering. At the time no laser surgery had yet been performed in Australia. To us it was extremely risky, especially as there were maternal risks. Added to this complex, and in our minds, experimental surgery was the fact that I had an anterior lying placenta. It was explained to us that an anterior lying placenta made the surgical procedure technically more difficult. I would have to fly to Brisbane if I wished to be assessed for surgery. The thought of leaving our 2-year-old, who was already quite distressed by the upheaval in our lives, and the 2-hour flight to Brisbane, plus the uncertainty of the procedure, led us to make the difficult decision to choose the more routine management of serial amnioreductions. By not trying to stop the placental blood flow problem we knew that we were continuing to place one or both of our boys at risk. In the end we felt that we made an informed decision. A decision that we felt was right for ourselves, our 2-year-old daughter and our unborn babies at that very moment in our lives.

During the next 9 weeks we lived from ultrasound to ultrasound, reduction to reduction. It was a roller coaster ride. I immediately quit work and tried to rest as best I could with a 2-year-old. She had 7-day a week care from family for the entire time until we brought her brother home from hospital 17 weeks after that first ultrasound. I found that the most crucial time that I needed to rest was after a reduction. I tended to have uterine contractions for several hours after each reduction and I found a combination of rest, listening to relaxation tapes and meditation assisted me in recovering from each reduction.

By the eighth reduction I was a pro, but I wasn't sure I would make it past the first reduction when as the needle was passed into my swollen uterus, amniotic fluid spurted forth like a geyser. I was soon able to predict when I would need a reduction — generally discomfort in my back, a hard stomach and difficulty taking a deep breath were good indicators, but I also became quite in tune with the boys movements. Once Max slowed down and I could not palpate his limbs, a reduction was pending.

I also became a bit of a pro at how my boys looked on ultrasound — I was probably the ultrasonologist's worst nightmare as I was asking questions one step ahead of the picture on the screen. Each time the image flicked up on the screen I would immediately look for two heartbeats. Then we would go through the checklist: brains; hearts (Max our recipient, had a ventricular septal defect and cardiomyopathy); abdomens — no excess fluid around any of the organs; Oliver's (our donor) kidneys and bladder; umbilical blood flow; estimation of excess amniotic fluid around Max; need for a reduction or not. It was so reassuring to see each of the boys moving — they always had their little heads orientated the same way — Oliver squashed down on the left and Max swimming around on the right. The first 6 weeks I needed a lot of fluid removed — I

became a pin cushion — this was always stressful, but at 25 weeks after 4.1 liters came off in less than 3 days the process seemed to stop and I didn't require another reduction. Those last 3 weeks were a little more reassuring as we felt we were being blessed with extra time.

During those 9 weeks after the diagnosis I did a lot of research and planning. As a "type A" personality this helped to ease some of my stress. I went on a high protein diet — with daily banana and egg smoothies and red meat or fish or both every day. I wrote and emailed regular updates to my family who were scattered across the globe so that all our family had the latest news. I kept a diary. We met with the neonatologist that would look after the boys in the Neonatal Intensive Care Unit to discuss likely outcomes when the boys were born. We made heart-wrenching decisions about when we would ask for life support to be given and when we would ask for it to be withheld. I drew up birth plans for pre 25 weeks gestation and then once we made it past 25 weeks I drew up a new birth plan and care plans for how we wished our boys to be cared for in the Neonatal Intensive Care Unit. It was important to us that if we were not with our boys that the staff looking after them knew how we felt about certain aspects of their care. I researched the effect of prematurity on family and siblings so that we could best prepare ourselves and Charlotte for the road ahead.

It was very important to me that my midwife continue to be part of my birth team, as I needed her emotional and psychological support for the rest of the pregnancy and at the birth. We spoke on the phone regularly and I visited her home office on the way to or from doctor's appointments for a "cuppa" and a reassuring chat. It was important that once the boys were born, Pete would go with them to the Neonatal Intensive Care Unit, but I did not want to be left alone in theatre and recovery with strangers. My babies were fighting for their lives and I needed a friend with me. My midwife was "with woman" not in her traditional sense but still with me nonetheless and her role in my birth team was vital. She was the steady, wise and reassuring voice among the mayhem.

All of my wishes in respect to my birth team, birth plans and the boys care plans were respected by the health professionals we came into contact with. This respect was so very important to my sense of being in some semblance of control in a situation that was totally out of my control. I felt that Pete and I were part of the team that was caring for this high-risk pregnancy and the very fragile little individuals that were to be born.

Nine weeks after the initial diagnosis, eight reductions, more than 13 litres of amniotic fluid removed, over 12 ultrasounds, weekly reviews with the obstetrician and meetings with the neonatologist and other hospital staff ... 9 weeks later, Oliver's heart started to fail — it was time for the boys to be born. Max (twin 1 and the recipient twin) and Oliver (twin 2 and the donor twin), were born at 28<sup>+1</sup> weeks' gestation. Our initial goal had been to get them to between 28 and 32 weeks' gestation — we just scraped in. I had a second dose of steroids the night before the boys were born; having had a dose at 25 weeks' when we had previously thought their birth was imminent.

Max, weighing 1220 grams, breathed at birth and went on to thrive. He did so very well in those early days. Oliver, weighing 960 grams, struggled for life from the moment he was born. After 6 days, his little lungs and heart were finding the struggle too hard. We agreed to turn off life support and he died in my arms cuddled up to his big brother and with his daddy kissing him. It was the hardest decision we have ever had to make. Watching life drain out of my little boy's precious face will live in my memory forever.

In the last 12 months we have ridden the biggest roller coaster ride of our lives. We have faced the devastating blow that a diagnosis such as TTTS brings, we have had the uncertain stress of imminent premature labour, experienced uncomfortable procedures, we have witnessed the premature birth of our babies and watched helplessly as they have fought for life, our hearts have broken as we watched our son die in our arms and our hearts have rejoiced as his brother has gone from strength to strength. We continue to live with the uncertainty of the possible long term effects on Max of the TTTS and his premature birth. We continue to mourn the loss of Oliver, our son, Charlotte's brother

and Max's twin. There are so many "what ifs". Despite knowing in my head that where we are today is where we are meant to be, my heart agonises over the events and decisions that we made.

We would not have made it through the last year without the love and support of our family, friends and community and without the professional knowledge and expertise of the health professionals with whom we entrusted our care in. We have been humbled by the overwhelming response from those around us that has come from such devastation.

Special thanks to our "team": Ms Annie Sprague, Dr Mark Umstad, Dr Lachlan de Crespigny, Dr Neil Roy, Dr Sue Jacobs, the staff of the Neonatal Intensive Care Unit at the Royal Women's Hospital, Melbourne and the Special Care Unit at Frances Perry House. Thank you for the care and respect you showed our family.

In loving memory of Oliver Kennedy Tyler, 28/3/2002 -3/4/2002, who came and left while the sun shone brightly one fine Easter.

