

Tom Cross  
By Gav Cross

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Tom Cross was born by emergency caesarian section on the 1<sup>st</sup> of February 2000. His mum, Cathy had been expressing concerns about the reduction of movement from him in the weeks before but had been told there was nothing to worry about. Cathy had gone into the Maternity Wing to see the birthing pool with her mum, as we had hoped to access it ourselves and happened to mention her concerns to a midwife. They listened to the heartbeat of Tom, called for a doctor and immediately Cathy was being prepped for the delivery in theatre. Our baby's heartbeat was fading in and out and if Cathy had not mentioned it then, who knows what could have happened.

Tom was born at 2lb 9oz, very much smaller in size than he should have been at the 8<sup>th</sup> month of the pregnancy. The whole birth experience was a traumatic experience, full of confusion, fear and frustration that if we had been listened too at the time of concern, this could have been a much smoother journey.

Tom spent 6 weeks in the Special Care Baby Unit. There was no reason that could be found for his size and though he was small he was perfectly formed! He had to get his size and strength up before we could get home.

As he was our first child we did not initially notice that he was not hitting some of his milestones. We knew there was something amiss because he seemed to struggle greatly whilst feeding, often unable to breathe properly and cry a 'silent' cry with a dusky hue to his lips.

After a routine visit by a community health practitioner, they suggested that they had developmental concerns and that they would talk about it the following week. At the doorstep, after being asked what the concerns were they said they suspected Cerebral Palsy and not to worry as they would talk more the following week.

This caused great distress and concern for both of us and a week to wait to talk about it seemed like an eternity so we immediately followed up that concern with Tom's consultant. He did not think that it was CP but that there was an underlying problem that a referral to more specialist services would clarify.

In the July of 2000, at the age of 5 months, Tom was particularly struggling with breathing and feeding and we took him to the hospital. The level of oxygen in his blood was monitored and it was very low. He was given a whiff of oxygen, by the afternoon he was in a head box of oxygen but that night he had to be intubated and immediately taken to the Paediatric Intensive Care Unit at Alder Hey.

This was to be the first night of our 15 month stay in that Hospital.

Intensive care was where Tom needed to be and we felt quite calmed that he was there but fearful that there was nowhere else to go if the situation got worse for Tom.

After a failed attempt to wean Tom off the ventilator we spent time having every test that could be given without any absolute answers coming through. Eventually the different teams that would stop at the end of the bed each morning would reduce as they pulled back from involvement and we were left with the reality that Tom would not come off the ventilator. Therefore a discussion took place as to ventilate permanently or withdraw ventilation then and say goodbye at that stage. Either option was one of a short and difficult like. The difference and reason why we made our particular decision to ventilate was Tom. Being able to breathe and get nourishment meant that he was thriving. He was a very alive boy in a body that was failing him.

After the operation for permanent ventilation and a gastrostomy was fitted we started the journey towards getting 'home'.

We knew we had to move to Liverpool, it was where the ambulance would take him and our house was difficult to adapt. We knew that the only way we could get him home was with 24 hour awake care and carers. From the day we went into hospital and for the next 6 years we never experienced privacy as a family again.

Cathy found a house that could suit our needs. With some remodeling we could have a family/Tom's bachelor pad downstairs and private family space upstairs to retreat to. We were told that the house would have to be adapted to meet his needs as a big 14yr old and that there was currently a 5 year waiting list for adaptations. And that we would need a lift so Tom could have his bedroom upstairs at a loss of a bedroom and that the suggestion was a dining room upstairs, to compensate for the loss of the room downstairs. Probably 30 to 40 thousand pounds of adaptations compared to the 15 thousand we had researched for our suggestions. Because we had been given a 5 year life expectancy in a recent meeting, the whole experience was demoralizing and emotionally catastrophic. Only when we both started crying where we told that there was a reduced waiting list for urgent cases and that their practice was not to read notes so that they could come in and get the difficult questions out of the way. Personally I feel that this meeting paid a huge price on us and our ability to trust that practitioners would be informed and interested in our ideas or aspirations and that a simple multi agency approach would have saved a huge amount of work, effort, tears and battles.

We were turned down for the shortened waiting list in the September.

We extended our mortgage and started the work ourselves.

In the October we were accepted as an urgent case but they would not give us any money for the structural, electrical and internal adaptations we had started. Including the conservatory to create the family space.

There was so little communication and information, we had to learn and discover or squeeze answers and detail from everybody. People who tried to help often got tired and stepped in and out. Only the Intensive Care Ventilation Consultant and the Psychologist were the two on the journey consistently, from start to finish. Many times we were not listened to as experts in our sons and families needs. We had to balance the clinical reality that Tom was an unknown quantity. Nobody knew what was happening and why at that stage and we were carving a new path, with the realities of a service that we had to fit too, even when an external review said it was not fit for purpose.

We knew that we were on strong partnership terms with some practitioners and seen as a nightmare to others. Why? On reflection I think it was we could never cope with an unqualified no. If the answer was no we wanted to know why and what the options were. We would battle. A practitioner once told me how lucky we were for getting the level of services we had. I felt many things about Tom, love, pride, guilt, despair, and fear. I felt lucky to be his father but never lucky that he needed the services. It taught us a salient point that even if what we got wasn't the right thing we needed, it was seen we were seen as never satisfied. And we were not.

Tom was a quirky boy in many lovely, personal and clinical ways. If a new Doctor came in, looked at Tom and then called for the huge amounts of notes before even talking to us, who had lived with it for years, we knew that there would be very little effort in investing time in them. So we created a sheet of Tom's quirks and our quirks as a family.

We hated having to take Tom into hospital, Tom's illness, our illness, a carers illness that often was phoned into us 15 to 20 minutes after the 6pm deadline for calling their manager had passed. We would not get call to ask us questions and we would arrive to find crash teams or isolation setups when a quick call to us would have resolved it. Perhaps they wanted to let us get sleep but what parent does not want to be part of the middle of the night emergency?

Here is an extract from that document:

Heart rate When sleeping, Tom's heart rate can go as low as 54 but averages at 65 / 70

Veins Tom has thread veins and getting a line in can be very difficult.

Trachy Leak This is under review. He has low tidal volumes and lots of secretions around the stoma site. His trachy must be inflated.

Circulation Due to the nature of Tom's condition his skin has various quirks all of its own. Tempa dots are difficult to use sometimes there is a reading sometimes they don't register at all.

Tom has a circulation problem that shows itself in different forms. It sometimes looks like red/purple finger marks on his upper arms; these tend to come out after a bath.

He also gets red marks all over his legs and arms that look and feel like bites (they sometimes feel raised in the centre). These tend to appear when

there is an increase in temperature, i.e.; hospital, central heating, too many covers etc. His feet and legs are also affected by cold and sometimes turn quite motley and purple.

#### Moving & Handling

Tom is very tall so is becoming more of a challenge to move. Even though we have said how dependent he is on the vent, we now move him short distances without ventilation, making sure that he is bagged once moved before being put on the vent. We also now roll him onto his side when we change his pants to protect his hips.

We consider ourselves the expert carers in Tom Cross.

We understand and accept the need to share our son's life with health care professionals and respect good practice in all forms of delivery of his care.

We appreciate partnership on all levels of Tom's care and want to be consulted at every stage of Tom's needs.

We would expect to be consulted as Tom's mum and dad over any issue at any time of the day.

We would like to be kept informed of any issue that arises around Tom's care, as it happens.

With Thanks Gav & Cathy Cross

We know some people found this very useful and some people found it very difficult. When the Family File arrived I saw it as a relief. If families could get this message down once, not have to go over it and remember every important fact, it would save so much time, stress and heart ache. I am eternally disappointed that people still see this as just another piece of paper. The fact that is information that is so much more important than the acres of notes written about the child and family still seems irrelevant and is a marker of a service not family focused provision.

After some years we did receive a diagnosis, SMARD1 Spinal Muscular Atrophy with Respiratory Distress. This gave us no new information but an important ability to diagnose if we had further children. 10 months after diagnosis, Libby, his sister was born.

This is when we needed to really get the right service for Tom and us. We wanted to protect Libby from the impact of adults around in the house all the time, the stress experienced by her parents. Financial struggle and everything that goes along with child with complex health needs. I had started to work for Early Support and was helping to develop a key working service in one area whilst still feeling lost and alone in our area. A colleague asked me the fatal question one day, "how are you" and that day my defenses were so low I didn't even manage the stock, "fine" answer. I shared.

Colette offered to meet Cathy and I and offered to key work for a short term to get a multi agency meeting together and make a fully rounded plan for Tom from a fully rounded picture. We had never had one and we were moving towards

self-managing the care package with the support of the PCT, out of desperation and despondency. Tom was 6.

I think we had about 25 key people in that meeting, finally. Decisions were made in an instant that we had been trying to get agreed for months. We discovered things we had never been told or given the option about.

A plan was made and a great relief was felt.

Tom was 6 and we had been on this journey for 6 years.

People told us they had not realised Tom was 'so ill'. People who managed his services.

The palliative care team had been involved with Tom at that point. Though we never expected it to happen so quickly, Tom caught chest infection and died a few weeks after that meeting. The time in between gave us a glimpse of what it could have been if all the teams and leads had talked and listened to each other from the start. It gave us a glimpse of what a key worker could do.

When Tom died, the final service we had to invite into our house was the funeral service. When we made our now traditional quirky requests they didn't say no straight away. They went away and thought about it. Talked some more to us and worked hard to meet our needs as best they could. It was a great relief to experience a no uphill approach at this stage of his life with us.

There are many other happy, sad, infuriating, joyous and beautiful tales about our time with Tom.

In the simplest terms. I truly believe that if we had an Early Support approach with key working for even half of Tom's life it would have saved time, stress, effort, argument, confusion, desperation and money for both services and us.

If you would like to see the video we made for the family service plan meeting you can find it here:

<http://www.youtube.com/watch?v=91e9PM26RNs&list=UUX7Xa8pG8tdVpQlsy6pLulw&index=2&feature=plcp>

Or hear more of Gav talking about Tom for the Anthony Gormley Trafalgar Square Plinth project, go here:

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