

3rd August, 2012

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BUNYA QLD 4055

To whom it may concern,

Following is my submission to the Inquiry into Palliative care and home and community care services.

My son Thomas, was born with a life limiting, undiagnosed condition in May 2007 and died in hospital in April 2009. At 4 weeks of age, we were told he would most likely not live past 9 months. His condition was 'officially' deemed palliative a year later, at his first birthday.

As Palliative Services for children did not exist in Queensland, Thomas did not receive specialist palliative care. We did not receive counselling, support, financial aide or respite relating to palliation. We did not know of any other families who had been through similar circumstances, and we were working in a hospital system that did not provide palliative care. Access to palliative care equipment and suitably qualified staff to operate such equipment, was difficult, confusing, bogged down with paper work and limited due to my son's age.

My husband and I have sought extensive counselling since our son's death, to come to terms with the difficulties we faced in the hospital system during our son's life. We believe that our grief would be lessened had we had adequate access to palliative care for our son.

Our wish is for a children's palliative care service to be established for the families of Queensland. We hope that no other family ever has to endure the inadequate care our son received. We hope that no other child and their family is left to fend for themselves in such a difficult time. We hope that children have the choice to die in a loving, supporting, non-hospital environment.

I have attached my son's life story (the medical version) and our wish list for palliative care in the future.

Thank you

Nicole Lipp

Mother of Thomas [REDACTED] 24th May 2007 - 22nd April 2009.

Our Journey with Thomas

The day my son Thomas was born was the single, most happy day of my life. His birth, a natural drug free delivery, made me feel invincible and gave me a beautiful, blonde haired, ruby lipped, blue eyed little boy. My love for him was immeasurable, the minute I touched his soft little head.

I was ecstatic. My nearly 2 year old daughter loved her new little brother, and my husband was delighted with his son.

Then late on day 3, one of the midwives noticed Thomas was cycling his legs and licking his lips. Immediately he was rushed to the hospital's special care nursery with suspected seizures and concerns about his head size. Two days later Thomas was transferred via ambulance to a major children's hospital in Brisbane, with my husband and I forced to follow closely behind in our car. (It was against protocol for a parent to travel in the ambulance and no helicopters were available.)

Upon arrival at ICU a doctor, who never introduced himself, rattled off a list of tests he was to perform on our son, many of which were intrusive and painful. And as I did not give birth to Thomas at this hospital, we were not allowed to stay in hospital with him. My role as advocate for Thomas immediately began. After 3 days of non-intrusive testing, consulting with many specialists and brain scans, Thomas was declared to have "hyperflexia" or an exaggerated startle reflex which should disappear by 8 weeks of age. Happily we went home, with an MRI booked for one month's time.

Over the next 3 weeks, Thomas began to show difficulties with waking and feeding. He was generally a happy, beautiful little baby but would have bouts of screaming and couldn't attach for a feed. Numerous consultations with our paediatrician and maternal health nurses did not help. In desperation we took him to the other children's hospital emergency department. Thomas was immediately admitted to hospital and referred for an urgent MRI and blood testing. We were told Thomas had significant microcephaly - small brain - and the outlook was bleak. "He will never walk, talk or have any meaningful interactions". We were told that the life expectancy of such babies was 9 months and that therapy wouldn't help him. It was suggested that we "take him home, feed him up and read to him". We were discharged from hospital with no referrals for therapy, no counselling, no support, just an appointment for surgery for a gastrostomy in 2 weeks time.

We were devastated, confused and in a state of shock. How could our beautiful, little boy be given such a future? How could we help him? Not only were we mourning the loss of our son's future, hopes and dreams, but we were left totally unsupported and terrified. We had no one to turn to for advice.

Feeling completely overwhelmed and fearful for my son, I asked for my church community to pray for him. At the end of mass a lady who worked for Mamre gave me her card and told me to call her. Soon we had the love and support of Mamre and Xavier Children's support network. They provided us with information, counselling and carers for in the home. They encouraged me to seek medical professionals who would support Thomas and value his life.

I started by 'harassing' the physiotherapist who had seen Thomas in ICU. She agreed to see him in outpatients and with her help, I also organised OT and speech therapy. Later they referred us on to FECS and Thomas had weekly therapy at home. I contacted Vision Australia and within weeks Thomas was having a ball at playgroup at Narbethong Special School. Thomas also attended music therapy, swimming lessons and private physiotherapy, all of which I had to arrange myself. I tried many paediatricians until I finally met Dr Tony who was prepared to "take on Thomas". Next we were seeing neurologists, hip specialists, gastroenterologists, dieticians - within 6 months, Thomas, Ella and I had attended 99 medical appointments!

Throughout it all, we worked hard to not only provide Thomas with a quality of life, but to ensure we took time to just enjoy him and be a family. We celebrated and were amazed by Thomas' strength. He learnt to roll and hold his head up. He ate solids. He loved looking at spotted things and he played with his sister and daddy. We celebrated his christening, and a birthday every 6 months. He grew more adorable. We fell in love with him.

At 6 months of age, Thomas began showing signs of frequent seizures and posturing difficulties. Thomas was hospitalised, further testing occurred, new medications were prescribed. We went home.

His condition deteriorated. At 8 months of age, Thomas' seizures worsened and he had episodes of severe high muscle tone. Hospitalisations occurred frequently. Medications increased, treatment options and quality of life decreased. Thomas began to lose voluntary movements in his entire body. Oral feeding ceased, he became sedated, he could no longer travel in the car or lie flat, his breathing became laborious and he began to choke. He now had an oxygen machine, a suction machine and a feeding pump. He could never be left unattended. We loved him more.

Being in hospital was incredibly stressful for Thomas and our family. Not only were the nurses unfamiliar with caring for a child with Thomas' needs, but they were working in a hospital system not set up to cater for kids like Thomas. Mistakes in his medications were made on a daily basis (on two occasions this resulted in near-fatal consequences), routine measurements were taken hourly regardless to whether they were relevant to Thomas' condition or not, and no considerations were made for the fact that we often spent weeks on end in hospital. Our sleep was continually interrupted and I began to lose hope. I would sob all the way to hospital, knowing how much of a battle I had ahead of me, to ensure appropriate care for my son.

Time at home was very precious. We moved Thomas into our bed, sleeping on his daddy's chest for most of the night. My mother came from Toowoomba every Wednesday to drive us to Narbethong. We became selective in which social events we attended, preferring to stay at home cuddling and loving our children. We went on a holiday at the beach. We held him continuously, drinking in his smell, savouring his touch, not taking a minute for granted. We took many photos, we

played, we sang, we read and laughed, we cherished our little family.

Nearing his first birthday, Thomas was admitted to ICU with pneumonia. Four days later he was moved to the general ward and we were told to prepare for him to die. We called our priest who came and administered 'last rites' to Thomas. We stayed awake all night, cuddling him, kissing him, taking photos and crying. He pulled through and we eventually took him home. We were told we were lucky this time. With help from our GP, we created an advanced health directive and planned his funeral.

The next month saw his breathing decline further and muscle spasms increase. As there were no paediatric services, an adult pain specialist was consulted. Continuous morphine was recommended. It was hoped to reduce his muscle spasms and breathing difficulties however, it would reduce his already limited life span. We were out of options. We agonised over the decision. A further decline in his breathing helped us decide. We began the morphine.

Due to the morphine, we were unable to take Thomas home until an in-home nursing service was organised. An adult palliative care service agreed to be our provider until they discovered that Thomas was 15 months old, not 15 years old. They could not provide medical care to our young son. Eventually our Xavier case worker became our in-home nurse.

Over the next few months, Thomas' health stabilised. We cherished this time and even managed an extended stay at my parents in Toowoomba for Christmas. Thomas grew into an even more beautiful little boy and now weighed a whopping 10 kg. He truly was our 'little man'.

Late January 2009 Thomas' muscle tone became high again and he began vomiting blood. Hospitalisation, testing, new medications all yielded no explanation. Thomas could no longer keep any food down. His organs were failing him, his body began to shut down. By Easter Thomas was still in hospital, so we arranged for all 4 of us to stay for the long weekend. Although in hospital, it was a lovely time - just being together as a family.

We had returned home for just 4 days when blood began to appear in Thomas' bowel movements. After a midnight dash via ambulance to hospital, we were told that there was nothing that could be done to improve Thomas' chance of survival. We had a choice: ICU to try for an osteopathic drip or general ward and wait and see if his body could pull through. We met with Dr Tony - he advised against the osteopathic drip as he believed that it would not change the outcome and he cared too much for Thomas to put him through such pain. Other specialists agreed. With broken hearts, we returned to the general ward and once again the 4 of us bunkered down in hospital. We cuddled Thomas with all our might.

Two days later, during his morning consult, Dr Tony informed us that he didn't believe Thomas would survive the day. We asked to be left alone with our son.

We cuddled him, took more photos, sang to him, cried and kissed him. My mum, my sister-in-law and his carer came in to say goodbye. Ella kissed him for the last time. We held him. He died.

We removed all his tubes, turned off his machines and climbed into bed with him. We held him till nightfall. I danced him around the

room for one last time, singing his favourite song. We kissed him and laid him on the bed with teddy. I turned back to look at him as I walked out of the room; my beautiful little man sleeping peacefully, golden hair shining in the glow of the night light.

Thomas Aaron [REDACTED], 24th May 2007 - 22nd April 2009. Our beautiful little man who lived close to our hearts.

Our Palliative Care Wish List

The following items are what we would like to see as a minimum for Palliative Care for Children.

• A Palliative Care Advisory service:

- a central organisation that families are referred to once their child's condition is deemed palliative.
- that can refer parents to paediatric palliative care specialists such as paediatricians, pain specialists, end of life care specialists etc
- advice on medications, equipment, financial aide, respite
- that can refer parents to counselling, support agencies such as Karuna Hospice etc
- that can educate parents on advocacy, the rites to care for their child, the rite to withdraw care etc
- advice on what death is like eg how does a dead child look, what is the process the body goes through etc
- advice on where the child can die. The implications of a child dying at home. The limitations of dying in hospital.
- that can provide a support network of other parents who have already been on the palliative care journey or who are also currently on that journey
- advice on funeral planning.

• A hospice/respite facility such as Hummingbird House:

- exclusively for children with life limiting conditions
- that supports the **whole** family
- provides live in care for the child and their family
- provides medical care to the child so that the parents can have a break from being the nurse and can just be mum or dad
- that can be somewhere for the child to go to die - in peace, without hospital routines, with respect and dignity

• Education for current doctors and nurses in our hospitals regarding palliation in children:

- that palliation does not mean to give up on the child (At one admission to hospital emergency, a doctor was refusing to put a drip in my son as he said that my son "was going to die anyway". To which I replied, "He is not going to die today so put in the drip". My son lived for 2 more months.)

- reassess hospital procedures to better cater for children with palliation needs. (is it really necessary to be still taking their temperatures hourly? etc)
- providing families with privacy when their child is dying (We had to ask to be left alone - ie no tea lady, no cleaning staff, no physiotherapist)
- a follow up once the child has died. We have never heard from the hospital again once our son died.

