

4th August, 2012

To the Parliamentary Inquiry Committee,

As a family we have experienced first-hand palliative care services in Queensland, primarily through the Royal Children's Hospital and Zoe's Place hospice. Our first child, Noah, was born in 2006 and was diagnosed with Spinal Muscular Atrophy, Type 1, when he was only five and half weeks old. He passed away at 5 months and 22 days old, in April 2007.

Our experiences caring for Noah, and our subsequent struggle with grief and loss have prompted us to provide you with our story and our comments regarding paediatric palliative care in Queensland.

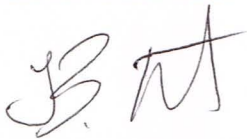
We acknowledge the difference that exists between disability and palliative care but we also recognise the cross over that is intrinsically linked for many children with complex medical conditions.

It is our hope that by sharing our personal experiences and recommendations we can contribute towards highlighting the need for continued change within the paediatric palliative care and disability landscapes.

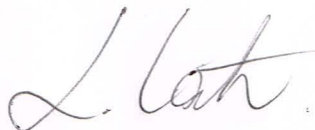
Please find attached a summarised version of Noah's story, including our experiences and relevant comments. We have also included a more detailed account of Noah's story that further supports our comments.

Yours sincerely

Brett and Louisa Carter



Brett Carter



Louisa Carter



Summary – Noah's Story

Noah Ennis John Carter

12th October 2006 – 3rd April 2007

Noah was our firstborn child, he was incredibly loved, wanted and cherished. Brett and I had been married for over 8 years when we finally had him. We had waited a long time to have children as we wanted to be sure that we were ready and would be the best parents possible.

Noah was born by emergency caesarean after a long and complicated labour. He weighed 10 pounds, 1 ounce, or 4.55kg, and measured 59cm long – he was a very large baby! He had beautiful blue eyes and the most gorgeous red hair – a trait my husband and I were so excited about! He was a beautifully calm and placid baby, he was alert and very aware of goings-on from only a few days old. He was smiling and frowning from around 2 weeks old!

Noah appeared normal for the first couple of weeks, however, after he failed to develop muscle tone and began to experience feeding issues, we investigated through several avenues before ending up in hospital a few weeks later with a diagnosis of Spinal Muscular Atrophy (SMA), Type 1. SMA is an autosomal recessive disease (both parents are carriers of the condition) which causes muscle wasting and mobility impairment. Type 1 is the most severe form of the disease, with sufferers rarely living past 12 months of age. SMA is the most common genetic cause of infant death (under the age of two).

We had never heard of the disease before, which is usually the case for most families who find themselves in our position. However, unlike most families, we were devastated to learn that another family member already had the disease (a cousin's child, with Type 2), but we had never been told what it was, never told that there was a significant possibility that my siblings and I carried this terrible disease.

We did our best to care for Noah, which wasn't hard really, as he was the most delightful and wonderful baby! We spent all our time and energy caring for him, making him as comfortable as possible, and giving him as many experiences as we could. He was a cheeky thing, he loved to smile, especially at the ladies – the prettier the lady, the bigger and cheekier the smile! He would raise and lower his eyebrows all the time – which only enhanced his personality and endeared him to us more. He also had fabulous cranky faces – anger, suspicion, sadness – he told them all with his eyes, and with his eyebrows as well!

Noah's story is so special to us, that it's hard to reduce it down to only a few paragraphs. So I have included a longer version which was used as a eulogy at his funeral, something I wrote during the week after he passed away as a cathartic and healing exercise. In the days following Noah's death, Brett and I felt such a sense of relief and peacefulness – we felt as though he was free of pain, free of suffering, finally released from his captive SMA body. It was easier to write at the time than it is for me to read now. But I have included it as we feel it contains vital information relating to the needs of families faced with the impossible struggle of infant terminal illness and end of life care.

As the time passes since we lost Noah, life goes on for us, but we only miss him more each and every day. The pain of losing our first child, and the seemingly impossible battle ahead to have any more children, for us, was very hard to bear. A little over two years after Noah passed away, we were finally blessed with a healthy, gorgeous baby girl, Mary – another big one at 9lb11oz (4.44kg)! She has her brother's pale skin, blue eyes, and of course, red hair. She is divine, and we love her to pieces! She was not a very happy newborn, but as a toddler, she found those cheeky eyebrows, and raising them up, impossibly far up it seems, is a party trick that never grows old! We didn't tell her to do it – it was something she did all by herself!

Noah continues to be very much a part of our lives. As Mary grows, we tell her more and more about him. She has known about him from the day she was born, his photos around the house, his toys, his gifts, even some of his clothes, are on display for her to see, touch, feel and experience. We celebrate his birthday every year with a special family outing.

We are desperate to have at least one more child, although this is very difficult for us to achieve. We began trying for another child in December 2010, and, after eventually seeking fertility treatment, finally fell pregnant in February this year. Unfortunately, genetic testing concluded that the baby had SMA, and we were faced with the impossible decision of whether or not to continue the pregnancy. Now we have another SMA angel, Rowan Elizabeth, our precious little girl lost at 16 ½ weeks.

Positives and Negatives of the Current System

Given our experience with Noah's short but important life, we feel we are qualified to make some comments regarding palliative and special needs care in Queensland. It is important to us that we add our story and our view to this inquiry, so that any families in the future who find themselves in our position, have the tools they need to make it through in the best way possible.

Positives:

- Our paediatrician was wonderful – she was pro-active and knowledgeable regarding Noah's care.
- The way our paediatrician liaised with the RCH made our experience there a good one – with her guidance, we were able to utilise this amazing service to the best of its ability.
- The specialist staff at the RCH were invaluable – they all did their jobs beautifully and obviously had a great desire to help families like us on our difficult journey.
- The majority of the nursing staff (non-agency) at the RCH were also great – they did as much as they could for us, which we appreciated considering they don't always work under the best conditions.
- Zoe's Place was a fantastic resource for us – both during Noah's life and after he passed away
- Zoe's Place provided us with practical support regarding Noah's care as well as emotional support for the realities his death would confront us with.
- We didn't actually visit Zoe's place while Noah was alive, they came to us shortly after diagnosis and in his final weeks as we had difficulty going out (we greatly appreciated them coming to us).
- Zoe's Place provided a great deal of support and comfort in the months after Noah's passing – we attended Group Counselling there and we can't express how much of a help this was to us. It was critical in our ability to cope with our loss.
- Xavier was an incredible help with the provision of a carer, 2 days per week (9am – 2pm), to assist us with in-home care. This was invaluable as it helped us be more rested and better able to care for Noah.
- Xavier also provided other support, including resources such as a hospital cot to assist with Noah's care at home.
- Heeson Medical Supplies gave us incredible support with in-home oxygen – this was so important as it meant we could be home with Noah in his final weeks, we had everything we needed supplied by them.
- Other organisations, such as Mamre and Montrose also provided support such as in-home physio and general assistance with day-to-day issues.

Negatives:

- When Noah was diagnosed, we saw a hospital social worker who gave us a list of names of support organisations that may be of assistance - that was all we got in terms of practical and emotional support.
- We had to research the organisations, contact each one in turn and co-ordinate their support ourselves. With the shock of diagnosis, caring for a newborn and still having all the usual time pressures of work, home and family, this was incredibly difficult and took away precious time we would rather have spent with our son.
- The level of nursing care in the hospital was incredibly variable due to the common use of agency staff. The nature of our son's illness and his palliative condition meant that agency staff were simply not equipped to deal with his needs. Permanent ward staff who dealt with Noah on a regular basis provided far superior care and this needs to be acknowledged by hospitals and addressed in terms of paediatric palliative care.
- The closure of Zoe's Place and the fact that there is no paediatric palliative care respite facility is truly an ugly blight on Queensland's palliative care landscape. Queensland is in desperate need of a facility that provides paediatric palliative care, temporary respite, end of life care and bereavement support.
- The journey of a parent of a child with a terminal illness does not end with the death of that child, our needs continue, and we feel this is an incredibly important part of paediatric palliative care.
- The mental health of the family left behind after a terminally ill child dies is of no interest to any of the current support organisations, and we feel this is a major failing of the current system.

Suggestions/Recommendations

- Not everyone has access to a great paediatrician like we did – this is critical to the journey of families caring for a terminally ill child. Every family in this situation should have access to a highly skilled paediatrician who is knowledgeable and experienced in the field of paediatric palliative care.
- Paediatric palliative care in hospitals needs to be correctly resourced, especially concerning nursing staff and their ability to cope with complex needs children.
- Specialised case workers are required for families immediately upon diagnosis of a terminal illness – this is critical particularly for families like us who have such a short period of time in which to care for their child. The time with our child was so short, and every minute we spent trying to gain assistance and support was one less moment with him – it is imperative that a system be put in place to help with situations like this. Families who have just been blind-sided with a terminal diagnosis do not have the emotional capacity to instantly deal with the “system” and there needs to be a case worker who can effectively take over and manage as many aspects of support as possible.
- Support for families after the loss of a terminally-ill child or baby needs to be on-going. These people need to continue to be addressed as patients – not just fall off the books and be forgotten about, as we have. We have had a huge amount of issues arising from the death of our child, including the on-going impact of our diagnosis on our life and future. For us this has meant a huge strain - physically, emotionally and financially in our quest to have more children and deal with the reality of life without our son. Noah lived for only 5 months and 22 days, but since we have experienced over 5 years of heartache and difficulty, none of which has been addressed by a single public organisation. We are fortunate to have private counselling provided through one of our employers – without which we would have no other psychological support without huge financial expense.
- Queensland needs a paediatric palliative care and respite centre. This facility needs to be built as soon as possible to fill the enormous gaping hole in the current system, where families with terminally-ill children have nowhere to go but hospital for paediatric palliative and respite care. The fact that Queensland families are forced to drive over one thousand kilometres to access this kind of facility in another state is proof that the current system in Queensland is failing dismally. It is appalling to think that in this modern age we, as a society, as a state, are not providing this for our most vulnerable citizens.
- We believe that Queensland Kids is an organisation with the potential to be a significant part of the improvement of the paediatric palliative and respite care landscape in Queensland. If this organisation were to be supported by the government, it will have the ability to fill this hole and complement the system to ensure improved outcomes for families like us. The system still needs to be improved, and it is imperative that alongside this, Queensland Kids be funded and enabled to provide the additional complex requirements of paediatric palliative and respite care in this state, starting with the building of Hummingbird House.

We would like our submission to make the point that paediatric palliative care services currently in Queensland are inadequate and do not address the highly complex needs of terminally ill children and babies, and their families, both during the period of illness, and after their death. The World Health Organisation recognises the specialised needs of palliative care for infants and children – Queensland currently does not. These children and their families are amongst the most vulnerable people in society, and they deserve to be better supported by the wider community. They need to be recognised for the incredibly hard road they have to travel, as well as the amazing job they do, everyday, caring for their children in the best way they can, given what little support they have.

The current systems are comprised of highly skilled, highly motivated and caring specialists and professionals. They are not the problem. The system in which they operate is preventing them from providing the amazing care they are capable of, that we were fortunate enough to experience, but disappointed not to have had the full benefit they could provide given a more effective and efficient system.

We, as a state, are letting these people down. Please listen to what we have to say, so that we can give the support to these families that they so deserve. No one ever thinks something like this will happen to them. When it does, your world falls apart and it never really all comes back together again. Most people don't travel this road, this is a small group of people, but what they have to endure surely qualifies them to deserve better.

Noah Ennis John Carter

Noah Ennis John Carter was born on Thursday, 12th October, 2006. After 41½ weeks of pregnancy and a long, unsuccessful labor, he was born by caesarian section at 6:15pm. He was a whopper! He weighed ten pounds, 1 ounce, or 4½kg, and measured 59cm in length, well over the average for a normal baby. The doctor's nicknamed him "The Bruiser" and the midwives commented on how easily they could see where Noah was in the nursery, as he took up a fair bit more of his plastic cot than the other babies! We stayed in hospital for four nights and went home on the Monday morning. The first couple of weeks went as expected, we were very tired but deliriously happy with our big and beautiful red-haired baby boy.

Noah was a great newborn, he didn't cry too much, he fed and slept well and was relatively easy to settle. He was breastfeeding well and putting on weight steadily. He loved to fall asleep on his Dad's chest. From birth, he was alert and happy whenever he was awake. His eyes would follow people as they walked in and out of the room, he would look right at you, and stare into your eyes. From the beginning, Noah loved people, particularly the ladies! He was a large baby, and while we noticed he was floppy from early on, we just assumed he was placid and calm, and, like his dad, just preferred taking it easy!

When Noah was around 2½ weeks old, we started to notice some feeding issues. I had struggled with breastfeeding in the first couple of weeks, but had managed to get a hang of things around the end of the second week. At first, Noah seemed to be coping with the flow of milk, which admittedly, was pretty fast and strong! We searched the internet for how to deal with such a fast flow, and tried everything we could to improve things. It was a hard time, as the first few weeks are for most parents, and we just assumed that we were dealing with run-of-the-mill newborn problems. We were determined to do the best for Noah, but after a week of trying, things didn't improve. Some other issues had arisen as well, such as Noah's lack of muscle tone, his quiet cry, the strange way he held his left hand, and towards the fourth week, his tendency, while awake, to breathe more with his stomach than his chest.

We visited a feeding clinic when Noah was exactly 4 weeks old. According to the nurse, I was doing a great job, but Noah seemed to be struggling for some reason. At 4 1/2 weeks, we took Noah to see his pediatrician, Cath, who instantly detected problems with Noah's reflexes and muscle tone. He had also not put on quite enough weight for his size and age. Cath ordered some tests, and asked us if we knew of any muscular conditions in our family. At first, we said "No," but then we remembered that one of my cousin's children, Eliza, had something wrong with her that affected her muscles, but we had no idea what it was. My parents are both from the UK and almost all my aunts, uncles and cousins live there, so we aren't terribly close to them. And although we had met Eliza twice, when she was 18 months, and 5 years old, her parents never said what she had, and we didn't pry (it's a British thing!) After seeing Cath, we went straight to my parent's house, to find out what they knew about Eliza's condition. They knew little more than we did, so Mum rang my Aunt as soon as she could for some information. When we saw Cath the next week we hadn't had a reply from the UK yet, but she said Noah was to be admitted to the Royal Children's Hospital (RCH) the next day for further testing and assessment anyway.

The first hospital visit was a frightening and upsetting experience for us. Noah, on the other hand, loved it. With his adorable red hair, and his cheeky smiling face, he immediately won over every specialist, doctor and nurse that saw him. He was the quietest, most well behaved baby in the ward. He slept a lot, but was wonderfully alert and happy when awake. He was even very good for all the tests he had to have, such as x-rays, an MRI, blood tests, as well as sessions with speech, physio and occupational therapy.

It was that first day in hospital, when Noah was almost five weeks old, that we first heard the term SMA. Spinal Muscular Atrophy. The fact that there was another child in the family with a muscular condition was a big indicator that this was it. And while we were in hospital, we got the news from the UK that Eliza did, in fact, suffer from SMA – but at the time, we had no idea what it was. All we knew was that Eliza couldn't walk or move around. Although different types of the disease and a very short life expectancy was mentioned, we assumed the worst was a wheelchair-bound child who may not live past their teens or twenties, and immediately began to plan for the reality of this future. It wasn't until a few weeks later, when the genetic test confirmed Noah's condition, that the fact that Noah would probably not even make it to his first birthday, finally began to sink in. We read all we could about the condition, learning the averages for life expectancy, the progression of the disease and everything involved in caring for a child with SMA and making them as comfortable and happy as possible.

While in hospital, we learned how to more effectively care for Noah, including bottle feeding, special diet, positioning, physio therapy and play. After 3 days of testing and therapy, we returned home. We tried to live life as normally as we could, although this was now a very difficult thing to do. While Noah improved in terms of feeding, he seemed to have a bit of a downhill run physically. While he loved his physio sessions, which we carried out 3 or 4 times each day, his movement seemed to decrease, and his abdominal breathing became more pronounced. Noah returned to hospital the week after his

first admission, for a special x-ray called a barium swallow, where the doctor's looked at how his swallowing mechanism worked. This confirmed his need for thickened fluid, which the speech therapist had already put in place. We were very upset that breastfeeding could have caused him to take fluid onto his lungs, but were reassured by the doctors that he was fine, breastfeeding had done him no harm and that bottle feeding for now was quite safe as long as the feed was thickened.

Over the next few weeks, we did our best to enjoy Noah, although for many of our family and friends, the reality that he would not be with us for long had not yet set in. Brett returned to work when Noah was about 8 weeks old, and I did my best to cope with Noah's needs alone during the day. It wasn't easy, considering Noah needed lots of attention, including physio, positioning, play and special feeding requirements. I also expressed up to six times a day so that Noah would have breastmilk packed with anti-bodies to keep him healthy. It was hard work, but my milk supply was impressive – the dietician at the RCH said she had never seen anything like it! We had a freezer full of breast milk in no time! Brett took lots of days off from work in order to help me and also give me some time out every now and then.

Noah's condition generally followed a pattern of a short plateau followed by a short period of decline, then another plateau. Each period lasted one or two weeks, so we would just get used to doing things a certain way, then things would change over a similar period of time, then a new norm would be set. This was incredibly tiring, as every time we felt as though we were beginning to cope, things would change. Noah visited the hospital at least every fortnight, mainly for physio and occupational therapy. He also had a dietician who carefully monitored his weight and nutritional requirements. He saw his respiratory specialist more and more frequently as his condition progressed.

We bottle fed Noah until Christmas, and during this time, we had the opportunity to take him places and do many things with him. We went to the movies, had walks along the bike track, visited Ikea once (I LOVE Ikea!) and the shops several times. We spent a lot of time at my parents house – I have a large family with lots of brothers, sisters, nieces and nephews – and Noah loved being with his family more than anything. My family and friends were an amazing support to us and we just couldn't have done it without them.

When his feeding deteriorated towards Christmas, Cath suggested Noah have a nasal gastric feeding tube fitted so that he could have a break from bottle feeding when he was tired. It was just in time, as Noah had his last bottle feed on Christmas morning. He had 100ml feeds six or seven times a day, using a large syringe attached to his tube. As this was time consuming and difficult, it was actually a relief when he needed continuous feeds towards the end of January. We learned how to use the feeding pump and borrowed a portable one so we could keep him on the feed when we went out. We continued to take him places whenever we could, even though this was becoming increasingly difficult with his equipment and his positioning in the car. But we did manage to do a few more things that we really loved, like taking him to the seafront, and going to Gold Class to see Casino Royale, which he loved!

Christmas was a highlight for everyone, except maybe for Noah, who slept most of the day. Every time the family was ready to open presents, Noah would fall asleep. He was finally awake during the afternoon, and we opened his presents with everyone there. He received so many lovely gifts from his family, we took lots of great photos and everybody had a great day, especially his cousins, who loved showing him their presents and helping him play with his.

Brett went back to work again in January, but continued to take days off here and there to help me and spend time with Noah. We had a great deal of help from support organisations like Xavier, Montrose, Zoe's Place and of course, the RCH. We had a respite carer two days a week, equipment such as the portable feeding pump and modified car seat, as well as social support for us and in-home physio for Noah. Family and friends helped out whenever they could, and as Noah's care became increasingly demanding, took care of many everyday requirements, such as housework, yard care, car cleaning, grocery shopping and errand running.

As Noah's condition worsened, Brett decided to take some extra time off work to spend with Noah. He stayed home for the entire month of February, and this was an incredibly special time for us. With Brett home all the time, I could go out now and then, have a rest or sleep and just generally have someone else to take over Noah's care from time to time. We were the only two people who were capable of handling every aspect of Noah's care, and although this was very draining, we understood that every parent feels this way about their child, Noah just took a little more work than usual. We were determined to do everything we could to make Noah's life the best life possible.

At the beginning of March, Brett returned to work again. He was very reluctant to leave Noah for any extended period of time, but felt better that I had more help to deal with Noah's care. In the second week of March, Noah had been a little unsettled, and his carer, Debbie, was very concerned about his increased secretions and that they had a little colour to them. After I woke up from my extra morning sleep, my Mum and Debbie thought it would be best to take Noah to hospital. I was reluctant to take him, but it was for the best, as when we arrived his sats were very low and they admitted him that evening.

They put him on oxygen to assist his breathing, although in hind-sight we realized this was not so good, as he relied on it too heavily and never came off it.

Only one of us could stay with him, so Brett slept in the parent's room and I slept next to Noah's cot. The next day, he saw his doctors and specialists, who advised he stay for a few days to monitor him and see if he would improve. His tests didn't return any serious infections, so it was assumed he just had a common cold and would need close observation for a few days. He was given a course of antibiotics to cover any possible infections. Over the first few days, he seemed to be doing very well. His secretions were no longer increasing or so colourful, and he could tolerate a lower level of oxygen during the day. We stayed with him almost 24-7, with Brett going to work directly from the hospital, and returning straight back each night. Family and friends brought food and supplies as we only returned home once during his two and a half week stay.

We expected to take him home after a few days, as his condition seemed to improve. But then this improvement stalled and his condition stabilized. The doctors didn't want him to return home until he could do reasonably well without oxygen, and during his second week in hospital, this appeared to not be possible. We desperately wanted to return home with him, but his respiratory specialist convinced us to give him a little more time to improve. Unfortunately, this didn't happen, and after two and half weeks in hospital, we returned home with Noah on oxygen. In an amazing twist of fate, my Dad was working as an oxygen courier at the time, and the hospital was stunned by how quickly and easily we were supplied with an in-home oxygen machine, several bottles for travel and everything else we needed for oxygen management. We were so truly blessed with things like that, and my Dad was so proud to be able to provide such an important part of Noah's care. The idea of him picking up all the equipment and returning it after Noah passed away broke my heart, but he insisted on it, and I have never been prouder of or more grateful for the strong and stable man my father is and the way he would do absolutely anything to help me.

It was a tough week when Noah returned from hospital. Brett worked everyday and I had to manage Noah's increased demand for suctioning during the day almost single-handedly. Brett took over the minute he walked in the door so that I could rest as I had to take Noah during the night as well. We celebrated Brett's birthday that week as happily as we could. We had a small family dinner on his actual birthday and we had a great night! We then had a barbeque on the weekend with the rest of my family and a bunch of friends. Noah seemed to have a great day, he was a little smiley in the morning and rested well early in the evening. However, about 7:30pm, Brett was holding him, and he thought he might be having some trouble with secretions, but when he checked more closely, Noah had stopped breathing! It was incredibly scary for all those who were there, as we thought we were losing him. I swear he must have heard my cries of protest, as Brett felt him begin to move slightly as we were holding him. My brother called 000 while we helped Noah continue breathing by suctioning him and turning up his oxygen. Half a dozen ambulance officers attended, by the time they all arrived he was breathing more regularly, but was still not stable enough. They took him into the hospital by ambulance, only one of us could go with him, so Brett went with Noah and I travelled in another emergency vehicle behind – thank goodness an ambo was driving because it was the hardest trip of my life!

When Noah arrived in emergency he was only struggling a little, and seemed to be improving well. He stayed in emergency for a couple of hours and then was moved onto a ward. It was quite late by this time and we stayed in the room with Noah as we refused to leave him at all. Noah's doctors saw him the next day and agreed he must have had a blockage in his throat from a build up of secretions and that he would be able to go home. He stayed in hospital all day for observation and we returned home that evening. We realized we would now have to be very careful to watch for this type of blockage again, as the progression of the disease meant Noah struggled to protect his airways, which meant he was at higher risk of such blockages and had more trouble clearing his secretions.

The next week, Brett decided to work from home as much as possible. He couldn't bear leaving Noah during the day, and we wanted to do as much as we could with him, but going out took a great deal of effort. Since Noah couldn't go out, we brought as much as we could to him. Anyone who wished to was encouraged to visit, as Noah was a very social little person who loved people and looking at their faces. We put movies on almost constantly for him to watch. He had been quite a screen addict from early on, and, during that week, he watched my personal favourite, "The Princess Bride", and finally finished watching Brett's favourite, the classic "Star Wars" trilogy. He also had extra visits from Mandy, his physio, which made him happy as one thing that Noah had loved from the start was his physio.

Noah's last trip to hospital was the week before he died, on the Friday, to see his respiratory specialist. She agreed with us that his condition had deteriorated significantly and it was time to think about managing his struggles with breathing, which were becoming more frequent and distressing each day. He also saw his dietician, his physios, including Mandy, for the last time. He had finally reached 7kg, but this milestone was bittersweet – he was no longer gaining significant weight. Over the

weekend, he had struggles with breathing during the night and we started to come to terms with the fact he was very close to the end.

In the last few days, we visited my parent's house and went to McDonald's for our traditional Sunday morning brekky. They were the last places he went. On the Sunday night, he slept in my arms for hours as that seemed to be the only way he would be comfortable. In the early hours, Brett stayed awake to suction him frequently enough so that he wouldn't slip into an episode of difficult breathing.

On Monday morning Noah had visitors, some close friends of ours with a young child. He wouldn't smile at the others, but when the child came over, he cracked a small one when he caught sight of her face – he loved other children most of all. He then had a pretty good morning, smiling at everyone who came to visit after that. Brett slept as everybody traipsed in and out, some of them unaware he was snoozing under the covers. Debbie came as usual and cared for Noah while we talked with the ladies from Zoe's Place. We knew our time with Noah was very limited now, and we wanted to be prepared as possible. Zoe's Place had arranged for someone to be there every evening from then on, and they also helped us begin to face the realities that Noah's impending passing would bring.

On Monday evening, Lee from Xavier came for the night so that we could get some sleep. Noah became distressed at about 3:00am, and I spent the next couple of hours cuddling Noah so that he would be able to calm down and sleep. I talk with Lee until she went home and Brett took over at 5am. My Mum came and helped as usual at 7am, and carer Debbie arrived at 9am, after which we both had a sleep, and my Mum went home. I couldn't sleep anyway, and Debbie came in after half an hour to say that Noah's breathing had become quite shallow. I cuddled him again, and he settled a little. Brett came in after a little while and we all decided Noah needed some medication to help him calm down and sleep a little better. I continued to cuddle him, and this, combined with the medication, seemed to give him some relief. After a while, he was settled enough to transfer him to Brett's arms, where he snoozed for a couple of hours. My sister arrived for lunch, and we all ate in Noah's room. Brett had to cover Noah with napkins so he didn't get food on him!

Debbie left at 2pm so we got Noah settled in his "indoor" pram – a small stroller my mum bought him to assist with moving him around the house, but he loved sleeping and resting in it as well. As he seemed to be sleeping soundly, Brett went to have a shower while my sister and I chatted either side of Noah's pram. We talked about Noah, and about things to do with his passing like his funeral and particularly, what to SMS when the time came. My sister said she didn't want to hear or read the words that he had gone, and so we were working out a code to send instead. It was just at this time that Noah stirred and opened his eyes, but he was calm and settled. Then he began to shallow breathe again like he had in the morning that worried Debbie. I went to let Brett know, but when I returned Noah had stopped breathing. I picked him up and cradled him in my arms while my sister banged on the wall for Brett to come. He came, wearing a towel, and cuddled Noah with me as he slipped away from us. It was a moment of pure peace and tranquility. He didn't suffer, he didn't struggle, he just slipped away in his pram, his favourite place to be. His close family, his Godmother, some of our very close friends and his pediatrician, Cath, all visited and said goodbye. Noah was at peace and was incredibly loved in his final moments.