

To Oliver - the best brother in the whole world.

INTRODUCTION

This book is an account of the short life of our brave daughter Zoe who died of a rare genetic disorder when she was seven months old.

The first part of the book details Zoe's life and the second part tells of how we, as a family, coped after her death. Our son, Oliver, was three years old when Zoe died and I describe the effect this had on him and how we answered his many questions.

There are many reasons for writing this book. First and foremost, for Oliver. He has been wonderfully understanding throughout the whole ordeal. His detailed memories of his sister, although now very vivid, will I'm sure fade as he grows older. I hope that in the years to come he will sometimes read this book and remember, with love and pride, how he helped us care for Zoe.

This book is also to say thank you to our family and our many friends whose support has been invaluable over the last few years. I hope it will fill in some of the gaps for them and answer any of the questions they didn't like to ask.

Thirdly, contained within this book are the answers to many questions that we needed to know. When we first knew of Zoe's diagnosis we had no idea how to approach Oliver and how to explain to him that Zoe might only live for a short time. There were no completely relevant books offered to us, and we didn't really know where to begin. But, we managed, and Oliver is now a well-balanced five year old. Maybe this book can offer some ideas to other families in similar situations and help them through a difficult time.

And, finally, I have completed this book for me. Whilst writing it I have relived all the joy, pain, excitement, despair and heartache. It has been extremely difficult, at times, to put into words the sheer depth of some of the emotions we felt, but I hope I have managed to convey at least some of our feelings.

PART ONE
AUGUST, SEPTEMBER, OCTOBER

"It's a girl!". The midwife's words were such a shock to us as we'd been convinced all through the pregnancy that this was another boy. It was 09.25 hrs on Tuesday 23rd August 1994 and our daughter, Zoe, had just arrived into the world after a very quick labour. She was perfect in every way and weighed 7lbs 2oz. Her birth had been induced early at 39 weeks of pregnancy. This was due to the fact that three years previously when our son Oliver was born he had ABO incompatibility which was severe enough to require a complete exchange blood transfusion. There was no easy way of predicting whether Zoe would be affected or not, so it was thought that early arrival and quick detection should reduce the severity of the problem should it occur. As we cuddled our new baby daughter we wondered if we could detect a slight jaundice, but, blood levels of the pigment bilirubin were within the acceptable range so it was agreed that we could take her back to the ward with us and the medical staff would keep a close eye on her. A telephone was wheeled into the delivery room and we began ringing family and friends to spread the news of the birth. My husband, Keith, rang his mother who was staying at our house caring for Oliver and he arranged to collect them both that afternoon and bring them to the hospital. My parents were on holiday with my brother and his family in Bournemouth so we decided to try and contact them at lunch time. Keith and I kept looking into the little cot at the tiny sleeping bundle and we really couldn't believe our luck. She was beautiful.

It was no surprise when, about three o'clock, we were told that the blood bilirubin levels in Zoe were rising and that she must go under the ultraviolet lights. She could still stay on the ward with me and an incubator was prepared in the nursery. Keith went off home to collect his mother and Oliver.

At four o'clock an excited Oliver arrived to meet his new baby sister for the first time. He loved her from the moment that he saw her. She was lying on her back in the incubator with a nappy on and two squares of gauze covering her eyes to protect them from the ultraviolet rays. He stood on tip-toe and gazed in wonder at the sleeping baby in the incubator. He had brought with him a present for Zoe which was one of his teddies that he had wrapped many weeks before and had kept in his bedroom waiting for the arrival day. In return, much to his amazement, Zoe also had a present for him! Keith and I had chosen a little Matchbox police car which we knew he would love, but Oliver just could not understand how she had got out to buy it!

By 5 pm on that first day Zoe's bilirubin levels were rising sufficiently for her to be taken to the Special Care Baby Unit (SCBU). I was not unduly worried, or surprised, as we had all been down this path before. Keith had, by now, taken Oliver home so I quickly rang him to tell him that Zoe was being moved before accompanying her to the Unit. The Sister of the SCBU was the same as when Oliver was admitted three years previously with the same problem and she remembered us all clearly. It was nice to see a friendly and familiar face.

As Zoe had taken well to breast feeding it was decided that I would continue to feed her but 'top-ups' of formula milk would be given via a naso-gastric tube after each feed. The Unit would ring the ward if I was required to feed my daughter during the night.

Keith came back that evening and we visited Zoe. She was now having double phototherapy and the levels were continuing to rise. Whilst we were visiting that night another baby was brought into the Unit. We recognised the

new father immediately. His name was Richard, and he was the husband of a friend, Ruth, who is a Staff Nurse at the hospital where I work. We had been patients on the Maternity ward together and we knew that we were both being induced on the same day. Poor Ruth was unable to deliver naturally after many hours of trying, and eventually had a Caesarean Section. They also had a daughter, whom they named Charlotte - a friend for our little Zoe....

Zoe remained in the SCBU for another three days. The bilirubin levels reached a plateau and then finally began to fall. I fed her four hourly, day and night, and she was topped up with milk and water. She looked well and alert.

Late on the Friday afternoon I was finally allowed to have my daughter beside me on the ward, and, at night, she was wheeled into the nursery with the other babies whilst I slept. It was wonderful to have her beside me and be a 'normal' mum at last. Zoe was still jaundiced and her blood was checked four hourly but the levels remained below that which required phototherapy. If the levels stayed constant and did not rise then I would be allowed to take her home the following day which was Saturday.

At 11 o'clock on Saturday 27th August an excited Oliver arrived with his daddy to collect his new baby sister and take her home. He was very proud, and he wanted to help with every little detail. He was most upset that the motion of the car sent his little sister off to sleep, and she wasn't awake when he and Daddy carried her, in her car seat, over the threshold.

After a lunch of fish and chips, interrupted by several phone calls welcoming us home, I looked at the various cards and letters which had arrived to celebrate little Zoe's arrival into the world. My parents called in at the house on their way back from their holiday, expecting then to go on and visit us at the hospital. They were most surprised to see us at home with Zoe, and Oliver proudly showed off his new baby sister. Keith's mum, Peg, arrived later that afternoon and then one of his brothers, Simon, and his girlfriend, Rachel, so by 6 pm there was quite a houseful welcoming the new addition to our family.

The next day more family visited. Kevin, another of Keith's brothers, with his two boys, Christopher and Nicholas arrived. Oliver and his cousins spent a very loud half an hour in the garden! Later that afternoon we took Zoe back to the hospital to have her blood bilirubin levels checked. These were finally falling

so we were discharged from the hospital on the understanding that we could return at any time if we were worried.

The Community Midwife, Rosemary, called daily and weighed Zoe. We knew Rosemary from Oliver's birth and we had tremendous faith in her. It was, then, slightly unnerving when on Day 9 of Zoe's life she appeared to have lost a fair amount of weight and had diarrhoea. Rosemary called our family GP Dr Searle Barnes, and he visited and agreed that Zoe should be seen on the Children's Ward at Southlands Hospital. This we did the following morning and saw the Consultant Paediatrician Dr O'Connell on his ward round. Stool specimens were taken from Zoe and he recommended that a 'close eye' was kept on her. A slight discrepancy in the midwife's scales and the hospital scales meant that she didn't appear to have lost as much weight as we previously thought so we all breathed a sigh of relief and took her home again.

The next few weeks passed by uneventfully. The Health Visitor, Sue, called at home daily to weigh Zoe and then we began going to the Baby Clinic on a Wednesday afternoon to check her weight and so on. She seemed to be feeding well and gaining weight. Oliver adored his new sister and spent every spare moment beside her carrycot filling her in on all the details of life and stroking her back.

One morning Keith and I were upstairs in the office while Oliver was downstairs eating a yoghurt sitting beside a sleeping Zoe. I heard him chatting to her so I went downstairs to find him spooning yoghurt into her mouth whilst she was still asleep! He thought that we hadn't been giving her any food and that she would be hungry!

We had a constant daily stream of visitors. Friends and relatives came with gifts and the poor postman was overwhelmed with parcels for our house. We have foreign students to stay with us most of the year, and many of them (approximately 80) kept in touch. Once they heard of the birth they all began sending presents for Zoe. We had baby clothes, toys and utensils from all over the world - Austria, Germany, France, Spain, Canada, and Norway. Their generosity was astounding.

On the 6th October Zoe and I had our six week post-natal checks. We were both seen by our GP and Zoe also had an appointment at SCBU for a routine

check. Our GP was happy with me but commented that, "This baby doesn't seem to relax her legs". This he found worrying but she was normal in every other way and so there seemed no need for concern. At Southlands Hospital that afternoon, during Zoe's six week check, the Senior House Officer noted her "excellent head control" as she could hold her head up and extend her neck for long periods.

Four days later, October 10th, it was Oliver's third birthday and many family and friends came to our house with cards and presents. He had a wonderful time and took great care to show his sister all the presents that he opened.

Towards the end of October we all went down with colds and coughs, and, one day Keith carried Zoe into the kitchen on his chest and said to me, "Guess who's got the cough?". We thought that she would shake it off in a few days so we weren't unduly worried. After all, many babies have coughs, don't they?

Zoe was still coughing a couple of weeks later so her Dose II vaccination, of Tetanus, Diphtheria and Polio, was postponed to a later date as the appointment card advised that no unwell babies should be vaccinated. She had had her Dose I four weeks previously.

NOVEMBER

Keith and I were both deeply asleep at 2 am on the night of 12th of November when we were woken by a choking sound coming from Zoe who was lying asleep in her carrycot by our bed. Within seconds we had picked her up and laid her on our bed. Her neck was rigid and every few seconds a cough / choke would rack her body. Although she seemed to be choking there was nothing that she could be choking on. Her mouth, which I had checked for any obstruction was completely clear, and her last feed had been four hours previously. In desperation we wondered if it was a form of croup as Oliver had suffered from this as a baby so we ran downstairs with Zoe and turned on the kettle and quickly began filling saucepans with water and putting them on the hob. I held a rigid Zoe, face down above the steam, but this didn't seem to help. The fact that she was, I think, still asleep didn't improve matters as she was not responding to us at all. Just as I was thinking that we would have to dial 999 for an ambulance the choking subsided and our peaceful, sleeping, relaxed Zoe returned. As a trained nurse, the helplessness of those few minutes of blind terror were indescribable. To watch my own baby unable to breathe properly but unable to help her was terrifying beyond belief. Eight minutes earlier we had all been deeply asleep, then suddenly we were thrown into the most terrifying time of our lives.

Keith and I took turns to stay awake and watch her for the remainder of that night. She woke in the morning at the usual time and I fed her. The cough though, had now changed, and there was a constant throaty rattle every time she took a breath. She was looking very pale and had dark rings under both her eyes.

I sat downstairs in an armchair in the lounge and held her all morning, rubbing her back and trying to get her to give a good cough which I felt would clear the 'fluid' in her throat. Peg called round at lunch time and she re-enforced our fears that things were not 'quite right' and so we called out the duty GP.

Dr Nelson arrived 15 minutes later and examined Zoe thoroughly. She felt that "things would probably be fine" but she wanted Zoe admitted to Rainbow Ward, the Children's Ward at Southlands Hospital, for observation. She made the relevant phone calls while I packed a bag, and when she, and Peg had left, we set off for the hospital.

Zoe received regular nebulizers and 24 hours later she was sounding better. She still had her cough, but it sounded looser and everyone seemed satisfied. Her paleness had been noted and her haemoglobin tested and shown to be within normal ranges, even if on the low side.

By now Zoe was 12 weeks old and had developed such a beautiful smile she would, literally, beam at people! It was during the ward round the following morning, when she was looking and sounding a lot better, that she gave the Consultant, Dr O'Connell, the most wonderful smile and he said, "There can't be much wrong with a baby that smiles like that!" and we were duly discharged.

As I work full time as a Deputy Sister at a local hospital and had taken Maternity Leave to have Zoe I was, therefore, due back at work when she was 14 weeks old. I had done the same when Oliver was born - having had just 18 weeks off altogether. He had been a larger baby (9lbs 10oz) and had gained weight quickly so was eating solids and devouring gallons of breast milk by the time I returned to work. I used to feed him at 6 am then go to work and Keith would bring him in at lunch time for a feed. I would sit holding a baby to my breast with one hand and a sandwich in the other! Our system worked very well

for several months and we were planning to do the same with Zoe.

So, on 17th November, whilst Oliver was at playgroup, Keith, Zoe and I went to see my Nurse Manager, Angela Bailey. We confirmed details for my return to work in a couple of weeks. She did offer me part-time work, but, being just before Christmas, and having been on half pay for several months we really needed my wages to return to normal. My agreed start date was 28th November.

Zoe's Dose II vaccination was due the following day but I still felt that she had not recovered from her cough so I cancelled it yet again and made another appointment for the following Wednesday when we would be at the Baby Clinic anyway.



We had kept in touch with Ruth, the nurse who had given birth to Charlotte on the same day that Zoe was born, and she and her husband came to visit us on the Tuesday morning. I was slightly perturbed as Charlotte seemed huge compared with Zoe, and she took her bottle feeds so well. Zoe looked pale and frail beside Charlotte but I put it down to the cough / virus that she had picked up.

That afternoon we went off to stay the night with a friend of ours who had just brought a house in Burgess Hill. Karen is a Staff Nurse, and she works on the Children's Ward at a hospital in Haywards Heath. She was to be Zoe's Godmother. Zoe was still coughing and was quite 'snuffly' that night, and, as I lay awake listening to her breathing I wondered what on earth we were going to do? We had commenced her on solids a couple of weeks earlier in hope of her gaining more weight, and, as I gave her some porridge early the next morning I decided that I would voice my fears to the Health Visitor at the Baby Clinic that afternoon.

At 2 pm and nearly in tears, I sat cuddling Zoe at the Clinic. She hadn't gained any weight, but she hadn't lost any either. She was still coughing and I was concerned. Things were just not right and I felt uneasy. I told my Health Visitor who, on seeing my concern, told me to see the doctor with Zoe. I arranged an appointment for the following day.

That afternoon I also made the decision to stop breast feeding and give Zoe formula milk. It was a reluctant decision as I felt in some way that I had failed her, but I couldn't see how much milk she was actually getting from me, and she wasn't gaining enough weight despite my feeding her almost constantly. Another reason was my imminent return to work, so I would not be around to continually feed her.

It was upsetting, and I came home to an empty house and cried. What on earth was happening? This was nothing like it was with Oliver. Keith, who had been walking along the beach with Oliver, returned and tried to reassure me that commencing bottle feeding was for the best, and that a lot of mothers have to change for various reasons. I felt slightly better and hot-footed it to Boots before they closed to buy all the necessary equipment. Bottle feeding was a whole new concept for us all.

I saw our GP the following morning, as arranged. He said that Zoe's chest sounded clear, which I found difficult to believe as her cough sounded so 'chesty', but he felt that her upper air passages were so small, and as she grew, things would improve. This sounded feasible. He prescribed some Ephedrine nasal drops to try and dry up some of the fluid bubbling around. I left the

surgery feeling slightly better - after all, if he wasn't worried, why should I be? The time came for me to return to work. On Monday 28th November 1994 I woke at 6 am and looked down at Zoe sleeping in her carrycot beside the bed. I noticed how far back her neck was extended, and I thought to myself what a odd position she had managed to get herself into in her sleep. I got ready for work and left at 7.30 am - Zoe was, by then, awake and having her first bottle of the day with her dad.

It was great to be back at work. Everyone seemed pleased to see me and I was continually asked about Zoe and how she was doing. But her cough, by now, was getting worse and worse. She also seemed to be holding her head back most of the time and her favourite position was lying on her tummy on our laps with her head held high, looking at the television.

DECEMBER

Oliver continued to dote on his baby sister. The week that Zoe had come out of the hospital following her birth he had started Playgroup, and, by early December he was enjoying his two mornings a week immensely. On his return, at lunch time, he would by-pass Keith and I and go straight to Zoe to show her his new creation or picture. Invariably they had been made especially for her, and never for us!

Around this time we contacted our local vicar, the Reverend Keith Wood, about having Zoe baptised. He called round to see us one morning and we set the date - Sunday 5th January 1995.

Preparations were now well underway for Christmas. Cards had been arriving for us from overseas for many weeks now, so on 13th December I had a day off from work and we decorated the house ready for the festivities. We planned a quiet family Christmas - just the four of us relaxing at home. Having a large house we normally entertain lots of family and friends at Christmas, sometimes as many as 15-20 people, so this was to be our first one to be spent alone.

On 15th December, whilst I was at work, Keith took 15 week old Zoe back to see Dr Searle Barnes as she was still coughing. This cough had now persisted for eight weeks - more than half of her life. He prescribed some antibiotics to see if they would help, and he also commented on the way that she held her head. Her neck was, by now, quite arched and she always seemed to be looking up at the ceiling. Oliver, at this age, had also spent a lot of time looking upwards - lights above him fascinated him for many months, and he would gaze at them for hours. Apparently, Dr Searle-Barnes had suggested trying the antibiotics, and then investigating her neck extension. It seemed to him to be a long term problem so there was no urgency just before Christmas, afterwards would be fine. Keith agreed.

December 20th was my dad's birthday and I had the day off from work. We all drove to Haywards Heath for a birthday lunch at my parents' house, and my brother, Richard, his wife, Hilary, and two girls, Claire and Amanda, were

there too. Zoe gave everyone huge beaming smiles and looked lovely in her pretty pink dress. Her cousins held her on their laps and she had a lovely day with lots of cuddles from all the family.

Two days later, December 22nd, Zoe's cough was worse than ever and she now had a temperature. Her chest sounded really 'bubbly' and she was having trouble taking her bottles with all the fluid bubbling in her throat. She sounded terrible and I just knew that we could not get through Christmas with her like this. I insisted that Keith took her back to the doctor's while I was at work the following day, Friday 23rd December. That day, as I dressed for work, I felt very uneasy. I gave my daughter a cuddle before going out the door and she coughed while I held her. It sounded as if she was drowning....

I was at work around 11 am when the phone call came from Keith to say that he had to take Zoe over to Children's Ward at Southlands Hospital as our GP wasn't happy with her condition and wanted her seen by the Paediatricians. I told my colleagues of the conversation. The Day Ward is an extremely caring environment and everyone insisted that I left immediately to catch the hospital bus to Southlands. By now I was upset - the nightmare had just begun, and, although I didn't know it at the time, our lives would never quite be the same again.

Less than half an hour later I arrived at Rainbow Ward and found Keith feeding Zoe, a bemused Oliver by his side. A nurse had checked Zoe's weight and temperature, and we were waiting for a doctor to examine her. It was a busy day on the ward, every bed or cot was occupied. At 3.30 pm the Senior House Officer (SHO) was free to look at Zoe. He gave her a thorough examination and took a detailed history, and then sent us off to have Zoe's chest X-rayed. As I am a nurse I was allowed to take my daughter to X-ray unaccompanied, and whilst I was there the full reality of the whole situation hit me. The radiographer gave me a lead coat to wear and then asked me to lie Zoe on her back for the X-ray, with her face looking upwards. Zoe just could not do it. Her neck was so arched that she rolled to either one side or the other. It was a physical impossibility for her to lie on her back - there was no escaping from the truth now - there really WAS something wrong with her.

Back on the ward the SHO looked at the films and came over to talk to us. He said that the chest X-ray showed some 'crackles' in her lungs which accounted for her cough, but, more importantly, he said, he was concerned about the hyper-extension of her neck as this could indicate a very serious problem. He mentioned the possibility of a brain tumour but said he would have to consult Dr O'Connell, the Paediatrician, and ask him for his opinion of Zoe.

Zoe was quite sleepy by now and she hadn't taken much milk all day. She still had a slight temperature and lay on her side in the cot sucking her fingers and sleeping fitfully. My colleagues from work rang on the internal telephone and asked what was happening. I spoke to them and I remember saying how horrified I was at the suggestion of a brain tumour, but I felt sure that as soon as the Consultant, Dr O'Connell, arrived he would dismiss such a theory.

At 6 pm Dr O'Connell arrived. He is a very kind man with a friendly face. I had met him several times when Zoe had previously been in SCBU and Rainbow Ward and I trusted him completely. After examining Zoe he, to my horror, agreed that a brain tumour was, indeed, a real possibility and an urgent scan of her brain was needed. It was, by now, after 6 pm and everywhere had shut down, over an hour ago, for the Christmas period. Dr O'Connell went off to make the relevant arrangements. The scanner is situated at Worthing Hospital,

which is approximately seven miles from Southlands Hospital, and phone calls were being made to call back the radiographers who had only just gone home. The brain scan was arranged for eight o'clock that evening and, as all the ambulance crews were busy, Dr O'Connell volunteered to take Zoe over in his own car. He also explained that, if the brain scan was normal then he would need to do a lumbar puncture to see if she had some sort of meningitis.

I was still dressed in my uniform (and I had been asked by several parents how their children were doing!) so Keith and I agreed that I would take Oliver home, feed him, change my clothes, pack an overnight bag and meet him and Zoe back at the Scanner Room at Worthing at 8 pm.

I arrived home to find the telephone ringing. It was Kevin's wife, Ingrid, who was ringing to find out what was happening. I recounted the story so far and replaced the receiver in tears. The telephone rang again almost immediately and this time it was Keith's mum. I briefly explained again and said that one of us would ring her after the scan. I quickly packed my overnight case and gave Oliver a sandwich to eat. I then debated when to ring my parents. I didn't want to worry them unnecessarily, but, then again, if I rang them later to tell them that Zoe DID have a brain tumour they would be totally shocked as they'd have known nothing about it. I decided to ring and tell them what was happening, and said I would be able to let them know more later on. They offered to come down and look after Oliver for us, but I felt it important that Oliver was with us and involved in whatever was happening. I thought it would have been more frightening for him to be taken away from us.

As Oliver and I walked through Worthing Hospital to the Scanner Room that night the corridors, all decorated for Christmas, were deserted. I could just not believe that only that morning I had gone into work as usual, and now, here we were waiting to find out if our daughter had a brain tumour. It all seemed so unreal.

Waiting for us in the ante room of the scanner department was Keith and Dr Bull, the Consultant Physician with whom I work. Anyone who is familiar with Worthing Hospital will know that the corridors are stalked at night by the locally famous Dr Bull and tonight was no exception. He had been walking past when Dr O'Connell and Keith had arrived with Zoe and he kindly stayed with us during the scan. Zoe was, by now, being prepared and she was heavily sedated so that she would remain still for the scan.

Apparently, Keith told me, that when the sedation was gently squirted into Zoe's mouth an hour earlier on Rainbow Ward she had choked on it and gone a blue colour. Dr O'Connell had seen this episode and had used the suction machine to suck out the secretions and medicine left in her mouth. Gradually her colour had returned to normal. The sedation had, by now, completely relaxed her and, for the first time in many weeks her chin was able to touch her chest.

Keith, Oliver, and I remained in the waiting room while Zoe's little head was scanned. I briefly recounted to Keith the phone calls I had whilst at home. After a while the door opened and Dr O'Connell came in and said, "Good news! No tumours, it looks completely normal!". We were lulled into a false sense of security - we thought that the worst thing that Zoe could have had was a brain tumour, and as she hadn't got this, then surely everything now would be fine? Whatever it was it was obviously less serious and less of a threat than a brain tumour. Instantly our spirits were lifted and we wanted to tell everyone the good news. She was going to be okay - she didn't have a brain tumour. Little did we know that this was the first of many negative test results, and this pattern of

intense worry then absolute elation was to be repeated time and time again.

When we arrived back on Rainbow Ward at Southlands Hospital Zoe was heavily sedated so Dr O'Connell took the opportunity to do the lumbar puncture while she was quiet and still. The results would be known later that evening, and, indeed, about 11 pm the doctor came to inform me that the fluid taken was clear. She did not have meningitis.

I spent that night on a foam chair that opened out to make a bed and I lay on the floor next to Zoe's cot. Keith had taken Oliver home so that they could both get some rest in their beds. Keith is a Registered Childminder and he had a new child and his mother arriving to meet him at our house the following day, which was Christmas Eve. He, therefore, needed to get some sleep before Ryan and his mother arrived. There were also some last minute Christmas presents that had to be delivered to our families houses, so Keith would come to the hospital when all these tasks were completed.

As I bedded down for the night I began to prepare myself for a very different Christmas to the one we had planned. As Zoe had only just been admitted to the hospital and such serious conditions had been discussed with us that evening I thought it very unlikely that we would be home for Christmas Day. I felt very upset for Oliver's sake and wondered what sort of Christmas was in store for him. Zoe was still sleeping off the effects of the sedation and she had not stirred. I fell asleep immediately whilst listening to the night nurses quietly chatting at the nurses' station just in front of me.

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I was woken by Zoe whimpering at 2 am and I jumped up to lift her out of the cot. Her skin felt very hot. One of the night nurses, Clive, on seeing me get up, came over and so I told him how hot she felt. He placed a thermometer under her arm and went off to make me a cup of tea and get Zoe's bottle. Several minutes later, another nurse, Tracy, came over and read the thermometer. Zoe's temperature was 39.8 C, which is high. She was given a paracetamol suppository to reduce her temperature, and an electric fan was plugged in beside her cot to cool her down. I removed her sleepsuit. She took a little milk from her bottle and then fell asleep again so I laid her back in her cot and got back into bed myself. Sleep then evaded me as I wondered why her temperature had suddenly gone so high, and what on earth could be wrong with our baby.

As I lay thinking on my makeshift bed on the floor, ward activity the next morning started. Lights went on and drug rounds began. It was Christmas Eve. Zoe was still sleeping so I took the opportunity to go and have a shower. As I went out of the ward I passed the day shift arriving and one of them was a familiar face to me. Rita had been a Nursery Nurse on the Children's Ward when I trained back in 1979 and I clearly remember her giving me instructions as a student nurse on how to make up the formula feeds for the babies on the ward. She also happens to be a very good friend of our lovely neighbours, Ann and Richard.

Rita was allocated to look after Zoe that morning which was nice for me as talking to her gave me some relief from constantly thinking about the events that were taking over our lives.

Zoe's temperature had gone down and she was still sleeping. At 9.30 am she began stirring. I changed her while Rita prepared a bottle of milk and I began to feed her just as the doctors were starting a ward round. Just as the

team of doctors, led by Dr O'Connell, approached Zoe she chose that exact moment to choke on her milk and turn a horrible horrible blue colour. I turned her on her tummy with her face down and hit her back hard several times but she was still blue and not breathing properly. A doctor shouted, "Put her on the bed. QUICK," which I did, and he used the suction machine to suck out the milk from the back of her throat, and then gave her some oxygen. Gradually her colour returned to normal. I was very shaky after this episode - all I kept thinking was, had we been anywhere else apart from the hospital we would definitely have lost her.

Following this brief interruption to their round Dr O'Connell instructed his doctors that Zoe was to have nothing else orally. A naso-gastric tube was to be passed and she was to have her feeds this way. He also asked that her oxygen saturation be monitored constantly which involved attaching a little probe to her foot which then displayed her blood oxygen levels on a screen by her cot.

Keith and Oliver arrived later in the morning and I took the opportunity to go to the Staff Restaurant and buy some sandwiches as it was now 36 hours since I had eaten. Zoe sounded very chesty, and moving her around seemed to make the coughing worse so we tended to let her lie sleeping in her cot most of the time. She was having regular nebulizers to try and ease her chest and the naso-gastric tube had been passed into her stomach. She was having small hourly feeds of milk.

My parents arrived in the afternoon and Keith suggested that I go back to our house with them and have a few hours rest, which I did. Oliver came with us and it was infuriating to be stuck in queues of traffic on the journey home - the whole world, it seemed, out in their cars in high spirits on Christmas Eve gathering their last-minute Christmas items. I felt very much that events were out of our control and I had no choice but to go along with this nightmare. We would get through it and then there would be another Christmas next year - at the moment our priority was to concentrate on our daughter.

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My thoughts wandered to last Christmas. I had suspected towards the end of December 1993 that I might be pregnant, but dared not get too excited in case it was not true. We had been trying for a brother or sister for Oliver for nearly two years now and I was beginning to wonder if something was wrong. A series of investigations had just proved negative, and now, there I was with my period two weeks late. By Christmas Eve I was almost convinced I was pregnant, so I hurriedly brought a pregnancy testing kit on my way home from work before the shops shut. Five o'clock Christmas morning found me in the toilet staring at the bright red dot that told me it was all true! I rushed upstairs to tell Keith of the best Christmas present that he could possibly imagine and we laughed and cried with joy.

How very different it all was this Christmas Eve. When we arrived home the Christmas tree lights were on, the decorations glistened and sparkled but all the excitement had gone. The phone call I had received from Keith at work just the day before had changed my whole world it seemed. In the couple of hours that I was at home friends called with presents for Oliver and Zoe, unaware of the problems that we had been facing. The phone rang repeatedly and I returned to the hospital at 5 pm having had little rest. My parents left the hospital around 6 pm I wanted them to continue with their planned Christmas at my brother's house and assured them that we would all be fine.

Within a few minutes of returning to Zoe's bedside a group of carol singers gathered around us singing 'Silent Night'. It brought tears to my eyes - all these hospital workers giving up their precious time to try and lighten our Christmas. Suddenly I was 'on the other side of the fence' having had, for many years, tried to ensure the patients had a reasonable Christmas, I was now on the receiving end and it was a very emotional time for me. A Father Christmas accompanied the carol singers and a wide-eyed Oliver was invited to delve into the sack that he was carrying and bought out a handful of sweets which pleased him immensely. Shortly after this Oliver and I left the hospital to go home for the night. Keith stayed with Zoe on the ward.

It was very sad driving home to a cold and empty house on Christmas Eve leaving Keith and Zoe behind. Once indoors Oliver hung his sack by the chimney in our bedroom and went quietly off to bed. I then filled his sack and then arranged all the childrens' presents around the tree downstairs before retiring to bed myself. It was, already, the worst Christmas I had ever faced.



Christmas morning I woke early, showered, dressed and waited for Oliver to wake up. At 8 o'clock he was still sleeping soundly and I was desperate to get off to the hospital. I stood on the landing and called, "Oliver". "Yes, Mum," came the reply. "I think he's been!" I shouted, and a tornado rushed along the landing. He was so excited when he saw his sack full of presents and dragged it up onto our bed. He opened the sack on the bed with me and then we went downstairs and he saw all the other presents. He was just so excited, but despite his overwhelming enthusiasm I felt so sad that this was just not how it was supposed to be and the tears flowed. As he ripped open parcel after parcel he kept asking, "But Mum, why are you crying? He's been. Look, he's been!". We then decided to take the rest of the presents to the hospital to open with Keith and Zoe, so I hurriedly dressed Oliver and loaded the car. We drove through the deserted streets to the hospital. Zoe had had a fairly peaceful night, and Keith had managed a few hours sleep in-between feeding her via the naso-gastric tube. She was sleeping soundly when we arrived and Oliver excitedly carried on opening his presents.

Around 10 o'clock our friend, Roy, arrived with his daughter, Katie. It was a lovely surprise as we hadn't thought that we would see anyone that we knew that day, and shortly after them Simon and Rachel arrived. It was wonderful to see them all and we opened a small bottle of champagne that we were going to have with our Christmas dinner.

Everyone on the ward was excitedly waiting for the arrival of Father Christmas, and following a visit from 10 local firemen in uniform, the gate opened and in HE walked carrying a large sack of presents for all the children. The ward was almost full of children this Christmas Day so we had a long wait until he reached Zoe's bedside. By prior arrangement Father Christmas gave Oliver his main present from us, an expensive construction set which we dreaded him giving to the wrong child! We recorded some of the mornings activities on our cam-corder, and to this day, these few minutes of Zoe on the video have become part of our special and precious memory of her. She spent her Christmas Day lying on her side in her cot, sleeping and sucking her two fingers. Her cough was terrible, and she was still wheezy and needing regular nebulizers. We tube fed her small amounts of milk hourly. To move her out of the cot seemed to encourage her to cough so we left her lying on her side, and

when she was awake we put our faces parallel to hers to talk to her. There were no smiles - she was too poorly, but she looked intently into our eyes. Her Auntie Karen had given her a toy Bambi for Christmas and this lay beside her in the cot.

Dr O'Connell visited Zoe twice on Christmas Day, listened to her chest and asked how we were all coping. In fact, for the next five days he came to see Zoe every morning and every evening, even when it seemed he saw none of the other children, he always saw Zoe.

On Christmas Day Keith and I stayed at the hospital to be near both Oliver and Zoe, but after this Keith stayed the nights beside her and I stayed the days. Oliver stayed at home with who ever was there at the time, and visited his sister twice a day at 'swop over' time. It was a very good arrangement and it meant that Zoe was never left alone, one of us was always there for her.

On 27th December it was noticed that Zoe's oxygen levels were continually dropping to between 80% - 90%. Dr O'Connell decided that she should be in a 'head-box' to give her a constant supply of oxygen and humidity and this immediately improved her levels and they remained between 95% - 100%. The head-box was a clear perspex square which rested on the mattress and enclosed the upper half of her body. Apart from making her hot and sweaty she suffered no ill-effects from the box and was still able to lie on her side sucking her fingers quite comfortably. Around this time a new friend for Zoe was admitted to the next cot. Her name was Sophie, and she was only a few weeks old. Sophie also had a cough. Her mum, Mandy, and I got on famously and we spent many hours sitting by our babies cots chatting. She and her husband, Stephen, also had another child, Alexander, who was a similar age to Oliver. Mandy and I provided great support for each other when we were feeling low, and, after a couple of days I felt like I had known her for ages.

As I mentioned earlier, I work as part of a small team on a busy Medical Day Ward. We are fortunate enough to have every weekend and every Bank Holiday off, a luxury not normally associated with nursing. Therefore, having had Christmas Day, Boxing Day and the following Bank Holiday off I was expected back at work on the Wednesday. I rang the ward Sister, Clare, at home on the Tuesday evening and explained that Zoe was still poorly. Without hesitation she told me to take as much time off work as I needed and not to worry. This was a great weight off my mind - although I wanted to work and not let my busy colleagues down, I knew that I couldn't leave my daughter alone in hospital when she was so ill. I began allocating Annual Leave days for the following week and hoped, at least, to get Zoe out of the head-box and back to

bottle feeding before I returned to work.

Many family and friends visited Zoe during the week between Christmas and New Year. New Year's Eve went by virtually unnoticed. Keith was at the hospital with Zoe, and I was asleep at home with Oliver. The words "Happy New Year" were meaningless even then, and at that time we had absolutely no idea that this was to be the start of the saddest year of our lives.

JANUARY

On New Year's Day Zoe's chest finally sounded slightly better and her oxygen saturation levels had improved. The head-box and the naso-gastric tube were removed. It was wonderful to cuddle her without having to quickly return her to the cot. I offered her bottles but she just wasn't interested so the naso-gastric tube was re-introduced - it was thought we had tried too soon. During the re-passing of the tube Zoe became very distressed and had another episode where she turned a horrible blue colour.

It was everyone's opinion that it would only be a matter of time before she would become interested in sucking from the bottle again, and so we tried encouraging bottle feeding before each naso-gastric feed when she was probably the hungriest. As her condition was improving Dr O'Connell began organising his team to arrange various tests to try and explain Zoe's neck extension. Several theories were under discussion. One was gastric reflux, the reflux of acid from the stomach up into the gullet, producing a soreness which can be eased by holding the head back. Another possibility was a neurological problem, therefore Zoe would see the Consultant Paediatric Neurologist when he came down from a London Hospital once every month. Various letters were written by the doctors and appointments made.

On 6th January I really tried persevering with her bottle feeding - I felt that we only had to crack this problem and then we could go home and have what ever other tests were needed as an out-patient. She did manage 50 - 60 mls of milk orally at some feeds but it was a real struggle. Inexplicably she seemed to have lost the ability to suck overnight.

That evening I left Keith at the hospital trying to encourage her with yet another bottle of milk. Somehow, over the day, her cough had again returned and the physiotherapist noticed an increase of fluid in her left lung. I was convinced that the milk was going there.

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The next morning, January 7th, I was at home at 7.30 in the morning when the phone call that I had been dreading came. I had been dressing Oliver when I heard the telephone ringing, and I knew before I picked it up that it was Keith with bad news. He told me that Zoe had stopped breathing in the early hours of the morning and it had taken two hours before the medical team could properly resuscitate her and get her breathing normally again. I remember asking Keith, "Is she still alive?" and when he said she was I quickly put Oliver in the car and drove to the hospital.

When we arrived at Zoe's bedside I cried. She was back in the head-box with the oxygen saturation probe back on her foot, a 'drip' in her little arm, and another tube down her nose and into her stomach. What had she done to deserve all this? Just as things were starting to improve we were now back to square one.

Keith was still shocked and upset over the night's events, and he was also very tired. I rang my parents and asked them to have Oliver for the day whilst we dealt with this crisis, and then I went back to Zoe's bedside to think. We had now been at Southlands for two weeks and although everyone had been absolutely wonderful to us we were still none the wiser as to what was wrong with our daughter. It seemed that all the specialist knowledge and tests she so desperately now needed were elsewhere, and time seemed to be running out

for us. Appointments to see a neurologist etc. in a month were no good to us now. I am normally a very placid person but now I wanted some action and I would go to any lengths to get the care that my daughter deserved. We had sat down and waited for long enough. I asked the nurses if Dr O'Connell was on duty and was told that it was his weekend off. I asked if he could be contacted. I had no doubt that, if he was in the area, and he knew that we were in trouble, he would come, but unfortunately he was away. Therefore, I asked if we could be moved to another hospital. A hospital specialising in children that had all the necessary equipment available (ventilators, and so on). The nurses agreed, spoke to the doctor and following several phone calls it was all arranged. We were going to Nicholson Ward at the Royal Alexandra Hospital for Sick Children in Brighton as soon as the ambulance arrived.

I accompanied Zoe in the ambulance with Sam, the Staff Nurse from Rainbow Ward, and Keith followed in the car. Zoe slept soundly all the way to Brighton, and when we arrived at the hospital we were shown to a small cubicle containing a cot, sink, chair and locker. Three sides of the cubicle were made of glass from waist level upwards, enabling the occupants to see out to the corridor and into the adjoining cubicles on either side.

We seemed to repeat the same story about the events in Zoe's short life countless times - to the nurses for their records, the Registrar for her clerking, and then around 10 pm that night to the Consultant Paediatrician, Dr Trounce. Time and time again we told the events of the night at home when Zoe choked and we tried to describe to them how she sounded. Dr Trounce felt that Zoe's symptoms were possibly caused by a narrowing or partial blockage in her airway, and that due to this she had learned to extend her neck to widen her trachea and help her breathing. All this sounded feasible, and a look down the air passages whilst Zoe was anaesthetised (a bronchoscopy) would confirm this. This test was to be performed by the Ear Nose and Throat (ENT) Consultant, Mr Tranter, on the Monday afternoon's ENT list in two days time. It was decided to observe Zoe until then, and because of the previous nights' episode she was to be kept starved, receiving her nutrition through her intravenous infusion.

Keith then went home to relieve my parents who were at our house with Oliver, and I bedded down for the night on a mattress on the floor (again!) by Zoe's cot. She was poorly, her cough had returned, and so had her temperature. Intravenous antibiotics had been commenced because of her probable chest infection, and she was very sleepy. Ralph, the night nurse who was caring for Zoe that night, was kept very busy as the machine regulating Zoe's infusion alarmed every time she moved or coughed in her sleep.

Keith and I decided that due to the increased distance now involved we would swop over once a day instead of twice, so each of our shifts would include one night and one day. Therefore, I was not expecting to see him again until 5 pm the following day. I spent the time sitting next to Zoe contemplating what her future may be. Did she have a partial blockage or a narrowing? If there was a partial blockage was it a cyst or a malignant tumour? The ENT surgeon came to see me that afternoon and he examined Zoe. He was a doctor I had worked with ten years previously on the ENT ward at Worthing Hospital and I knew that he was very good at his job. He explained the procedure, and mentioned that he'd seen a child with similar symptoms a year previously and that child's problem had been a narrow trachea which had corrected itself as the child grew. I have to admit, though, I was shocked when I signed the consent form and saw the words, "Oesophagoscopy, Laryngoscopy, Bronchoscopy, and

"proceed to Tracheostomy" written. Although this would have been the most obvious natural progression of events it was a situation that I had not even considered and it was a real shock to see it written in black and white, and applying to my child. Mentally I began preparing our house to care for a baby with a tracheostomy - converting a bedroom into a medical room with all the necessary equipment in.

The following day, Monday, Keith and I were both with Zoe as she was prepared for the anaesthetic. The Anaesthetist had requested an oral pre-medication which I was unhappy about. I knew my daughter well enough to know that she couldn't tolerate fluid in her mouth (we had had enough blue episodes with antibiotics at home and milk in the hospital to realise this). I questioned the method of administration and the Anaesthetist was contacted. He stuck firmly to his guns and oral pre-medication it was to be.

At 1.30 pm two nurses, Sally and Maraid, came into the room. They had the drug in a syringe ready to dribble into Zoe's mouth. Keith and I were very apprehensive, and, as the liquid entered her mouth she began to gag and choke. The nurses abandoned the procedure and the Anaesthetist was contacted. He promptly changed the pre-medication to an intramuscular injection.

Half an hour later Keith and I were carrying Zoe in the lift down to the second floor where the operating theatres were situated. Maraid, Zoe's nurse, was with us. We kissed Zoe's forehead in the Anaesthetic Room and left her with Maraid while we went back up to her cubicle to wait. My dad arrived while we were waiting and we were all sitting chatting when the door opened, and in walked Dr O'Connell from Southlands Hospital. He greeted us like long-lost friends - shaking Keith's hand and kissing me on the cheek, apologising profusely for not being there when we had needed him the most. He asked about the events of the weekend, and after telling him this we told him of the current theories regarding Zoe's illness. He added that he was pleased that we were now in Brighton where there was more specialised paediatric care and that he hoped we would soon receive some answers. He also added that he had seen a few cases of children presenting with bizarre symptoms for which no cause had ever been found - despite investigations at many hospitals, including Great Ormond Street Hospital. This was the first time that Great Ormond Street Hospital had been mentioned to us and I dismissed the thought almost immediately, feeling sure that within the next hour we would have our answer to the problem. I had already worked out that a bronchoscopy alone would only take about half an hour, where-as a tracheostomy would take an hour or two,

therefore the longer that Zoe was away from us the more likely it would be that she would return with a tracheostomy.

Dr O'Connell left us to go and speak to Dr Trounce about Zoe, and five minutes later a smiling Mr Tranter, dressed in his theatre blue's, came into the room saying, "Normal!". Keith and I were silent. He spoke again, "Everything looked completely normal. All her tubes looked the correct size for her age and nothing was seen to explain her symptoms". We were flabbergasted, and he must have thought us quite odd as we did not share his joy. Certainly, it was good news that she did not need a tracheostomy, but if there was no narrowing and no blockage then what was there that could have caused such major symptoms? Part of me felt that following the weekend's events at Southlands Hospital when Zoe had such a major episode, they, only then realised the seriousness of the situation. Now we were in new surroundings and I felt that she now had to prove to all these people that she had a problem, and, no-one here would fully understand until they too had witnessed it. This unfortunately meant that we had to wait for her to have yet another episode.

That night Zoe was nursed on the Intensive Therapy Unit. This was because, following the trauma of the investigation her small air tubes were likely to become inflamed and this inflammation, if severe enough, would require treatment with a temporary tracheostomy. We were not out of the woods yet!

Keith and I both sat with her for a while on ITU and Mr Tranter and Dr O'Connell both came back to see how she was doing. Later Dr Trounce came and said he was "very surprised at the findings and would have to go away and have another think". Later, Keith went home to relieve my parents of Oliver and I slept in Zoe's empty cubicle, safe in the knowledge that she was being continually watched and monitored by a nurse on ITU. I had a lovely sleep, then relaxed in a hot bath the next morning.



We had made up our minds from Day 1 that one of us would be with, and watch over, Zoe day and night. Despite the emotional tie of never wanting to leave her side, there was also the practical side - no-one could tell when she would suddenly develop difficulty with her breathing, and despite constant reassurances from the staff that she would be closely monitored we felt that she should be actually watched continually. Obviously busy wards do not have the staff to do this. The saturation probe on her foot was constantly alarming when she moved, or if the probe fell off, and the staff respond time wasn't always instant - losing seconds could be vital. Yet again I felt that we had to prove our case, and until they had witnessed an attack they would not worry. Hence, Keith or I were always with Zoe, 24 hours a day (unless she was on the ITU) and, if we left the room to go to the toilet, or have a meal, or make tea we always insisted that a member of staff stayed with her. The nurses were very good about this and never minded sitting with her for five or ten minutes.

Zoe had a good night on ITU and was transferred back to Nicholson Ward the following morning. The next investigation, a barium meal was scheduled for two days later on Thursday 12th January. Keith and I were both present for this which proved, yet again, normal. The barium was introduced into the stomach via the naso-gastric tube as our graphic descriptions to the radiographer of events following the introduction of liquid into Zoe's mouth were enough to dissuade him from doing this.

Following the normal findings on Zoe's stomach, naso-gastric feeding was once again re-introduced, and the drip in her arm was removed. The

antibiotics had improved her cough and she really was quite bright and gave us lots of smiles. We were moved to a larger cubicle across the corridor which had a bed in an adjoining room which, at night, we dragged around next to Zoe's cot so that we could watch her. The room also had a television in which helped pass the time of day when Zoe was sleeping. It was now 14th January and my concern was growing over the length of time I had been off work. Zoe had now been in hospital for over three weeks and we were nowhere near finding out what was wrong with her. She seemed stable enough at the moment, full of smiles, and not coughing too much. Her feeds were still given via the tube and we were trying to encourage the sucking reflex to return with the use of special exercises designed for babies who have forgotten how to suck. I decided that I must return to work. Keith would stay with Zoe, and my parents and Keith's mum would look after Oliver during my working hours. I could leave work if Zoe's condition changed and I could get to Brighton in 30 minutes if necessary. It was not an ideal situation, but I knew that life must go on.

So, on Monday 16th January I returned to work. It felt very strange but it was nice to be 'normal' once again. The two phones at work ring constantly and each time I heard the words, "Yes, I'll get her for you", my heart nearly stopped, but, thankfully it was never about Zoe. After the 10 hour shift I went home, changed and drove over to the Royal Alexandra Hospital to spend the night next to Zoe. The following day, Tuesday, was my day off which I spent with Zoe whilst she underwent a pH study. This involved inserting a special probe into Zoe's oesophagus - the end of the tube sitting just above the opening to her stomach. The probe registered the acidity of the gullet to determine whether reflux of acid from the stomach was occurring or not. The probe was to remain in place for 24 hours. The next day I took an Annual Leave day as I wanted to be with Zoe when she travelled to Brighton General Hospital for a Magnetic Resonance Imaging (MRI) scan. Keith accompanied her in the ambulance and I followed in the car. Maggie, Zoe's primary nurse escorted her, and Zoe was heavily sedated with a drug given via the naso-gastric tube earlier. She was, once again, all 'floppy'. None of us were allowed to be with her when she had the scan and I willed her not to have one of her episodes in this environment which was alien to us all. Luckily she didn't, and we all returned to the Alex several hours later.

Both the pH study and the MRI scan showed no abnormal result. Brighton were running out of ideas.



By now Zoe had been moved to yet another cubicle further down the ward. Rain water had been leaking through the roof of the previous cubicle and now we were back to having a tiny cubicle just managing to house a cot, bed, sink, locker and chair. On the Thursday I returned to work at 8 am, finished at 6 pm changed, had a quick meal with my mum and dad and, as they were staying overnight, Dad quickly drove me over to Brighton to visit my daughter. While we were there Keith took the opportunity to go and have a bath. Dad was sitting on the end of the bed reading a newspaper. Maggie, our nurse, came into the cubicle and she and I began chatting so she sat on the edge of the bed next to my dad. With an almighty crack the whole bed broke and they both fell together on to the floor! Staff came from all over the ward to see what all the noise was about, and Maggie kept slapping my dad's leg and roaring with laughter! Dad became quite a celebrity!

After work on the Friday I went straight over to Brighton to relieve Keith. Zoe was not so well. Her cough had returned with a vengeance, but she was still 'chatty' and smiled a lot. I was to be with Zoe until Sunday night when Keith returned with Oliver.

On Saturday I gave Zoe a lovely bath and massage and then dressed her in a little navy and white striped, short-legged, romper suit and little white socks. We had the most wonderful morning, Zoe and I, and what happened next remains my most perfect memory of her. I was lying on the slanting broken bed with Zoe sitting on my lower chest facing me. Every now and then I lifted my head and said, "Boo", whilst shaking my head from side to side. The more times I did this the louder she laughed, and every time she laughed, I laughed, until we were both loudly laughing our heads off. I was most embarrassed to see all the doctors on the ward round peering in the window as we were disturbing them!

Around lunch time our nurse for the day, Cheryl, came in and we discussed whether Zoe had oral thrush. We both felt that she had, and Cheryl went to get some medication prescribed for this. At 2 pm she returned with a tiny amount (probably about 0.5 mls - 1.0 ml) of nystatin suspension in a syringe. Zoe was sitting on my lap and Cheryl gently squirted the liquid into her mouth. Zoe stopped breathing immediately and turned navy blue. I remember shaking her and Cheryl telling me to lay her down on the bed. I was keen to run and get help but Cheryl kept saying, "No, she's fine, she's coming back to us. Just leave her a minute". Zoe took a breath, then another and another and gradually her colour and breathing returned to normal. At last they had witnessed an episode which Cheryl then had to repeat to the doctors time and time again, but still they were none the wiser.

At midday the following day I had a very strange experience. I was sitting in the rocking chair whilst Zoe was sleeping in her cot and I was thinking about a friend of mine, Clare, whom I hadn't seen for about three months. At that exact moment she walked in the door! It was very odd, and for the first few minutes all I could say was, "I can't believe it!". It was lovely to see her, and we recounted some old times as we had trained together as nurses some 16 years previously. Keith's brother, Simon, and his girlfriend, Rachel, then arrived but, by now, Zoe had woken and was crying and I felt uneasy. I had the feeling that something was wrong as she was getting distressed for no apparent reason. I then discovered that she had a dirty nappy, with diarrhoea, and the crying seemed to be associated with this so we thought maybe she had some wind. Paracetamol via the naso-gastric tube calmed her and she slept peacefully.

I returned to work on the Tuesday knowing that Zoe's condition was deteriorating. Great Ormond Street Hospital had already been mentioned to us and a bed had been booked for Zoe on Peter Pan Ward for the following Monday. Brighton could just not get to the bottom of her problem. I visited her after work and didn't want to leave her again, but I had to work the next day so needed to go home to get some rest. The following night when I visited she was even worse, and Keith was looking very tired having been up all night holding her hands. I reluctantly left the hospital at 9 pm and went home to bed. In the middle of the night I woke with a start. It was 3 am and I just knew that Zoe was in trouble. I thought I had heard her crying which was woken me up. I lay there for the rest of the night just waiting for the phone to ring but thankfully it didn't. At 6 am I got up and rang Nicholson Ward - Zoe had had a very bad night with one episode in which she required oxygen and suction. When I asked what time this episode had occurred I was told, "3 o'clock". I think it was when I put down

the telephone that morning that I realised that we would probably lose her. She was just so poorly, and no one knew why. It was a terrible thought and I was completely powerless to do anything to help her.

I tried to pull myself together before I arrived at work that day, but it was no use, and I arrived in floods of tears. I stayed at work, needing to be occupied, knowing that Keith would ring me if I was needed. The one thought that I couldn't shake from my mind was what we were going to write on the flowers at her funeral.

At lunch time my good friend and colleague, Rhona, arranged with the other staff that she would take me over to Brighton to see Zoe. It was a complete surprise to me, and I was very grateful. Zoe was looking very sick and I asked the nurses in Brighton if she could be transferred straight to Great Ormond Street Hospital that day. Apparently that possibility had already been explored by the doctors but no beds were available at Great Ormond Street. It was terrible having to leave her in that condition but there was nothing I could have done if I'd have stayed. I had one more day, Friday, to work and then I was to spend all weekend at the hospital with Zoe before she was transferred to Great Ormond Street Hospital on Monday.

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When Oliver and I arrived at the hospital on Friday night Zoe was sleeping. Keith and I had a brief chat and Oliver had a quick look at his sister and they left for home. I found I was very nervous in Zoe's company now - I jumped whenever she coughed and watched her like a hawk. She was back inside a head-box because her cough and chest were so bad. Every time she cried she became blue and needed more oxygen. I just knew that something was about to happen and about 3.30 pm on that Saturday afternoon she began crying inconsolably. I lifted the head-box to see her more clearly and as I did this she stopped breathing. I hit the panic button and no-one came (I hadn't kept my foot on it for long enough) so I ran off down the ward and barged into Sister's Office. She, and the person she had been talking to, came running back with me, and the Sister had to 'bag' Zoe several times before she started breathing again. Gradually her breathing and colour returned to normal. Following this episode Sister thought it best that Zoe be transferred to the ITU. I felt like saying that this was exactly why we had been with her watching her closely 24 hours a day for the last five weeks. At last this hospital had witnessed an episode - just as we were leaving to go to Great Ormond Street Hospital!

The above episode was preceded by a naso-gastric feed which may, or may not have been connected with the events. It was decided that all feeding should be stopped for the time being.

Zoe remained stable on the ITU until the following day. After lunch I was sitting watching her sleeping. I was feeling very nervous as I had a feeling that yesterday's events were about to be repeated, but the staff kept reassuring me, saying, "Just because it happened yesterday, it doesn't mean it will happen today". But I knew, beyond a doubt, that it would.

Around 5 pm Zoe started crying. She was beginning to sound strange again so I lifted the head box just as her breathing stopped again. There was only one nurse, Zoe and myself in the ITU. The nurse bleeped the SHO and started bagging Zoe and, when the phone rang I answered it and asked the SHO to come immediately. This time Zoe did not come straight back. She lay on the bed with her neck arched backwards, her eyes fixed and staring,

struggling to breathe. The SHO didn't really know what to do and called the Registrar. She came and called the Surgeons. I asked if they were thinking of doing an emergency tracheostomy to help her breathing but I was told that it was due to her 'rigid abdomen' that a surgical opinion was needed. I sat next to Zoe, holding her hand, whilst all the doctors were buzzing around. Aloud, I was pleading with her just to hang on until her daddy arrived. Keith was due at the hospital any minute. It was 5.30 pm I kept being asked if I wanted to wait outside but there was no way I was leaving my daughter if she was dying.

I talked and talked to Zoe as the nightmare continued. The Registrar ordered a nebulizer for her as she felt that she was having severe bronchospasm. Zoe's terrified eyes continued to stare and she must have been, literally, frightened for her life. She tried and tried with all her might to carry on breathing. It was a terrible fight to watch. One nebulizer was given, and a slight improvement noted so another was given. Staff were arriving from all over the hospital to help and the Radiographer was also summoned. It was now 5.45 pm and I was still stroking Zoe's blue / grey forehead and telling her that she was doing just fine. She was really struggling to breathe and I remember telling her that Daddy would be there any moment. The Radiographer, when he arrived, wanted an upright X-ray of Zoe's chest which involved her sitting up and leaning back on a foam triangle. I moved away from her side to allow the nurses to position her and I waited outside while the X-ray was taken. Keith arrived at this moment and I was just so relieved to see him. I couldn't have beared for him not to have been there if she had died. When we both went back into the room Zoe was still propped up on the foam triangle and when she saw her father she gave the most enormous smile! It was just beautiful, and everyone in the room was laughing and crying. She was back! We held her and cuddled her, and Keith then asked what all the fuss had been about!

Once Zoe was settled I gathered my bags and left Keith in charge - he was doing the London run in the ambulance with Zoe the next morning. Saying goodbye to her was very difficult. I kept going back for one last look, not knowing if I would see her again.

I found where Keith had parked our car and sat in the driver's seat and cried. I cried with relief because she had not died, and with sadness because of the suffering I had just witnessed. I had fully expected her to die just then, told myself that she would, and now, suddenly, she was okay again. But for how long? How long before she does it all again, and will she pull through next time? If only she could hang on until the next day when she went to London maybe, just maybe, they would have the answers.

It was about 15 minutes before I could drive off, and now I had to function normally again - drive to Keith's mum's and pick up Oliver, then go on to Haywards Heath to my own parents. My dad was coming with me to London the following morning and Oliver would stay with his grandma. I collected Oliver, who was streaming with cold, and began driving the 24 miles to Haywards Heath. I had not long left Worthing when a red light began showing on the dashboard of the car. On stopping to read the handbook I discovered it was the brake fluid level that was low. Not knowing if it was safe to continue driving I stopped at a country pub to use the phone. It was 10 pm and pitch black. Oliver had, due to the cold air, now developed croup and was barking like a seal in the back of the car! Whatever next, I wondered?! I eventually made it to my parents house about 11 pm having stopped at my brother's house on the way for him to check the car.

The following morning Keith was going to ring me at my parents house when he was leaving for London so that Dad and I could also begin our journey to London. By 10 o'clock he hadn't rung me so I rang the ITU to see what was happening. The journey was apparently under discussion. Zoe, although stable overnight, was now considered too unfit to travel to Great Ormond Street Hospital so maybe the journey would have to be postponed a day or two. A decision hadn't yet been reached (and this was why Keith hadn't rung me) but, as soon as it was I would be informed. I just couldn't believe that having waited so long to go to Great Ormond Street she, maybe now, was too ill to get there. Fifteen minutes later the nurse rang with some wonderful news - a medical team from Great Ormond Street were actually coming down to collect Zoe - they would probably ventilate her at Brighton so that she would have a safe journey back to London, and they had already left. The relief I felt was tremendous. All the stops were being pulled out for our little girl, and, with all the sick children in the country, they were coming to get OUR daughter. I felt very privileged. I wanted to be with Zoe when the team arrived so Dad drove me back to Brighton, leaving Oliver with my mum.

When the Retrieval team arrived in Brighton the Anaesthetist, Graham, from Great Ormond Street did intubate and ventilate Zoe, and Keith, Dad and I waited behind screens in the Brighton ITU while this was done. Afterwards we were allowed to see her, and, for the first time in many weeks we could relax. She could now not stop breathing while she was on the ventilator, so, temporarily at least, she was safe.

Keith accompanied Zoe and the team in the ambulance up to London. It is not normal practice for relatives to go in the ambulances with the children, and it took some persuading for them to take Keith. Our argument was that we had not left Zoe alone in five weeks, and we were not leaving her now. One of us wanted to be with her, whatever happened. Reluctantly, they agreed. They sped up on a 'blue light' and completed the journey in just under an hour. Zoe was heavily sedated and ventilated so the journey went smoothly. Dad and I drove up, and, as we had left Brighton before the ambulance, we all arrived at Great Ormond Street at the same time. Within minutes of transferring Zoe over to her cot she was surrounded by a team of doctors headed by the Consultant Intensivist of the Paediatric Intensive Care Unit (PICU), Dr Robert Tasker. He examined Zoe quickly, but thoroughly, and reeled off a series of investigations he wanted his team to carry out. He then spoke to Keith and myself and told us of a few possible conditions that could be causing Zoe's symptoms. He mentioned the Cytomegaly Virus, Mycoplasma infection and some other disorders which can be detected in the blood. He also asked us if anyone had told us that Zoe had an enlarged liver and spleen. No one had.

I was very impressed with Dr Tasker. He seemed extremely intelligent and had already summed up the situation and discovered something new. He was also very kind and friendly - asking about Worthing and telling us that he went to school in nearby Steyning.

Zoe was in a cubicle to the left of the nurses' station, and because she was ventilated she had a nurse with her continually. The ultra modern room was full of highly technical machinery, her heart and respiration rates, blood pressure and oxygen saturation were all constantly monitored and displayed on a screen above her cot. A computer beside her was for recording all her nursing notes.

The hospital organised a temporary bed for Keith that night in the basement of the hospital. Parents were not encouraged to sleep in with their children as it was felt that they needed their vital sleep. Keith had an appointment the following day with the Accommodation Officer who we hoped would help find us somewhere cheap to stay in London. Dad and I decided to leave for Haywards Heath about 9.30 pm that night. There was still Oliver to consider, who, as yet hadn't spent a night away from home on his own, so I wanted to get back to him. Mum and he were waiting up when Dad and I finally got back late that night and they wanted to hear all about Zoe's journey and her new hospital. I felt confident in leaving Zoe that night as she was still ventilated and both Keith and I knew that she couldn't stop breathing all the time her airway was permanently maintained.

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Keith and I had planned to do shifts of a week at a time with Zoe in London for the remainder of my Annual Leave, but, after Keith saw the Accommodation Officer he then managed to find us all some family accommodation in a nearby house owned and run by a charity - the Sick Children's Trust. Rainbow House was a rambling eight bedroom, four storey house which helped to house as many families of sick children as possible. Oliver and I arrived there the following day and met some of our new house-mates. These were people from all sorts of walks of life with one common bond - a sick child. There was tremendous empathy in the house and an understanding that came from complete strangers. In the large kitchen which was in the basement, there was a poem on the wall. I couldn't read the words from beginning to end for many many weeks but when I did they made perfect sense...

Within these walls may we find strength
to meet the challenge at hand.
Lend support to each other
and overcome the demands.
We'll take each day as it comes
and do what needs to be done.
Even though this may mean
endless hours without the sun.
The waiting and the hoping,
the frustration and the tears
will perhaps be lessened
as will some of our fears.
Simply being together
will bring us comfort and rest.
Knowing somehow we'll get through this
will make us do our best.
For in the centre of all this
is a child who needs us near
who needs to be held in our arms
and be told he / she is brave and dear.
When this time of our lives is over
and we recall what we shared,
we'll remember being together,
love, and people who cared.

Yes, within these walls
that were built with love,
we found friendship, courage, and peace.
We continue to hope and pray that soon
our child's suffering will cease.
Our days will be filled once again
with sunshine from above.
And hold in our hearts
all that we learned
within this house of love.

One couple we made great friends with were Ros and Bill. They had already been at Rainbow House for a few days when we arrived and they made us feel very welcome. They lived in Kent and had come to London as their seven year old daughter, Sarah, had a swelling on the side of her face and neck. Sarah was undergoing various investigations, and, to save travelling to London from Kent several times a week they stayed in Rainbow House.

The house itself was wonderfully decorated and furnished. Much of the decor had been provided by large organisations such as Marks and Spencers or Laura Ashley. The house had a playroom which was well equipped with donated toys and Oliver immediately made friends with Sarah and they amused themselves in the playroom. Soon after my arrival at the house I met Rose Lucas who was responsible for allocating the bedrooms and for the general running of the house. She was a ex-nurse who was employed as House Manager by the charity and she had her office on the ground floor of the house so she was a friendly face most mornings at our breakfast table. Rose proved to be a valuable friend during our stay in London - always showing concern for us, and also for Zoe's welfare. She frequently left us her home phone number so we could contact her at weekends if there was anything she could do to help us. We never rang her, but it was a lovely thought.

FEBRUARY

The night of Wednesday 1st February was the first night that Keith, Oliver and I had spent together since 23rd December. As Zoe was still ventilated, and was being continually watched by the nurses, we had decided to spend the days with her and the nights at Rainbow House. This way some resemblance of family life was maintained for Oliver, as he had only seen one or the other of us for the last six weeks. We were given a pager by the Sick Children's Trust so the PICU staff could bleep us if we were needed. This allowed us slightly more freedom in the weeks to come. On Zoe's brighter days one of us could go to the supermarket and stock up on our food supplies without continually wondering if we were needed at the hospital, or we could take Oliver over the road to the park.

Soon after Zoe had arrived at Great Ormond Street she was found to be anaemic so she was given a blood transfusion. An organism called 'mycoplasma' was isolated in her blood and we were told that this could account for her cough, anaemia, and enlarged liver and spleen. Antibiotics were commenced. Events seemed to be moving fast now that we were in London, and, if this micro-organism could account for all of the above then we thought we only had her neck extension to explain. Everything was looking quite hopeful! The ENT doctors came to see Zoe and agreed to repeat the bronchoscopy on the Monday (in four days time). We felt quite optimistic.

Zoe's sedation was gradually lightened and on her third day in PICU she was taken off the ventilator. She was awake and smiling, although still coughing, but all we had to wait for (we thought) was the correct antibiotics to work. As she was now off the ventilator she was moved to a three bedded bay of the unit, and her cot was now situated to the right of the nurses' station just inside the entrance. Keith, Oliver and I arrived on the Unit around 9 am every morning and Keith and I sat by Zoe's cot until 6 or 7 pm every night. Pamela, the Play Specialist for the PICU was wonderful at entertaining Oliver for us. She took him shopping to the local supermarket to buy ingredients, and spent many an afternoon with him in the small PICU kitchen making cakes or playdough. Much to everyone's amusement Pamela 'forgot' the cakes that were cooking one afternoon and the resulting smoke set off the fire-alarms throughout the hospital! She was constantly reminded of this disaster, and, consequently, whenever the fire alarms went off the chorus went up, "Pam's been cooking again!".

One afternoon Pam gave Oliver a huge piece of paper, about six foot wide by 10 foot long, and some brightly coloured paints. She asked him to paint a picture and, being only three years old Oliver haphazardly coloured the paper bright red, yellow, and blue and named it 'fireworks'. Nevertheless the painting was labelled with Oliver's name and age and put up on the wall in one of the corridors. Oliver was very proud and showed all our visitors his picture.



Considering how far away from home we were we didn't expect to have many visitors. How wrong we were! Most days we were lucky enough to see someone that we knew and that was a real tonic for us. Word got around of where we were now living and the post also started arriving every day for us. There were cards, letters and flowers for Keith and I from people that were thinking of us, and parcels of toys and books for Oliver. Everyone's kindness was

overwhelming.

Oliver was more than a little perturbed over our new abode and he kept asking when we would be going back to "our other house with the garden by the sea", and, "Why have we now brought this house, Mummy?". He also missed his own toys. Leaving home so soon after Christmas meant that he had a lot of new toys back home that he hadn't had a chance to play with. It was a shame but there was no alternative if we were all to be together. As we were now living in London, and Oliver had never seen London before, one afternoon Keith took him to see some of the sights. The pager ensured that I could summon Keith back to the hospital at any time and he and Oliver had a lovely afternoon travelling on the Underground and seeing Buckingham Palace. Our good friend, Rhona, had previously told Oliver that he must "be sure to knock on the Queen's gates to see if she is home", so Oliver insisted on walking the length of The Mall that cold afternoon in February to do what he had been told!

While Keith and Oliver were away from the hospital that afternoon Zoe was visited by one of the Neurologists, Dr Jane Collins, and her Registrar, Penny. It was really a preliminary visit as everything depended on what was found on Monday's bronchoscopy. If the bronchoscopy showed a problem then we had our answer, if it didn't, then Zoe's problem could be neurological. Dr Collins had come to say hello and read Zoe's notes so she would be acquainted with the case should her help be needed. Zoe had had several apnoeic attacks since coming off the ventilator, usually whilst coughing or crying. She chose the moment that I was talking to Dr Collins at the cot side to have another mild one. She began to cry. I was watching her intently, and also trying to concentrate on recounting her history when I saw her colour begin to change to a dusky blue. I called the nurse, who didn't hear me, and Dr Collins loudly then called, "Nurse, Nurse, can you come? Quickly!". She and I stood back whilst the nurse quickly bagged Zoe and the episode passed.

At the end of our conversation Dr Collins and I said our goodbyes and she said she would only be seeing us again if the bronchoscopy was normal. I said goodbye confident that I wouldn't be seeing her again.



Later on that day Zoe had an ultrasound scan of her brain and this was yet another test which was normal. Keith and I were absolutely sure that there was nothing wrong with our daughter's brain. We felt elated that each time a test was 'normal' and our theory was supported. To us, Zoe seemed too intelligent for there to be a problem in her head - her eyes saw, followed and recognised us, she smiled, chuckled and talked to us - she seemed, mentally, at that time, just as Oliver had been at that age.

Soon after the mycoplasma organism was isolated in Zoe's blood we were told that Keith, Oliver and I would also need to be tested to see if we were infected aswell. Oliver was very brave, having his blood test to help his little sister. All our results were clear.

Our first weekend at Great Ormond Street Hospital should have been Zoe's Christening weekend. Before we had left for London I had telephoned Father Woods to explain our predicament and the Christening had been postponed until further notice. Keith and I were both brought up with Church of England backgrounds but neither of us are particularly religious, and we never go to church. Nevertheless, I was very keen, initially, that Zoe should be baptised. This enthusiasm, I think, came about for three reasons : firstly,

pressure to do the 'right' thing ; secondly, if the child then decided as an adult to actively partake in the religion then baptism had already occurred ; and thirdly each child in the family should be treated equally (Oliver had been baptised, and therefore, so should Zoe). Keith was not so bothered but agreed that, if I felt strongly enough about it, I should go ahead and organise it, which I had. Father Woods told us he was very sorry to hear of the situation that we were in, and I promised that I would keep him informed of any further events. I do remember that it crossed my mind around this time that it might not be Zoe's baptism that we would be discussing, but her funeral. I kept such thoughts to myself.



In the cot next to Zoe in the PICU was a small coloured baby boy who was ventilated. His name was Peter and he had been born several weeks prematurely. His parents lived a long way away and could only visit occasionally. Peter had been in the PICU for many weeks and the staff knew him well. His condition lately had been causing concern and he seemed to be wheezy a lot of the time. There was, opposite Zoe, a little three year old girl called Chelsea. She was also ventilated as she had head injuries from falling from her top bunk bed at home. Chelsea's mum stayed with her every day - they also lived a fair distance away, and her father had to work so he could only visit at weekends. Chelsea's sister was being cared for by her grandmother. Hearing of other peoples' situations made me realise how lucky we were. We were all still together with Zoe and I had another two weeks Annual Leave due to me, which would take us up to 20th February. A lot could happen in two weeks, as I already knew, so I was quite optimistic that Zoe might be diagnosed and treatment begun in time for me to return to work. I felt that if I knew WHAT was wrong and what treatment would be involved then we could plan for, and deal with, whatever long-term problems came our way. I could then return to work in Worthing, leaving Keith and Oliver with Zoe, and I would go up to London for my days off until Zoe was discharged. It was the not knowing what was wrong that was the hardest part of all.



Around this time we met Tracy whose daughter Victoria had had a brain haemorrhage. Victoria was eight years old and one of identical triplets. Tracey had said goodnight to her daughter one night at home and had gone upstairs half an hour later to investigate a strange noise. She found Victoria fitting and vomiting. They had been sent to Great Ormond Street Hospital from their local hospital in Luton where Victoria had suffered a cardiac arrest. Victoria was also ventilated and had been at Great Ormond Street a few days longer than Zoe. Keith and I often chatted with Tracey, and her partner Mark. The different ages of our children was irrelevant - we were both in the same boat of not knowing if our children would live or die.

Simon and Rachel came up with Peg on that first Saturday. On the Sunday my mum and dad came up to visit us and Keith had managed to obtain two tickets for an open-top bus ride around London so he and Oliver set off around 11 am and had a lovely few hours in London.

The next day, Monday, Zoe went to the operating theatre and had a Micro-laryngoscopy and Bronchoscopy. It was normal. To our dismay Zoe was

now under the care of the Neurological team. I think we sensed that this could be the worst possible scenario.

Within Great Ormond Street Hospital is a Play Centre which accommodates both patients and their relatives who are residing at the hospital for long periods. We were very lucky in the fact that Oliver was able to attend the Play Centre every day between 9.30 am and 5 pm. He was able to play, paint, dress up, make pictures, read, listen or watch entertainers all under supervision, which allowed Keith and I to concentrate on Zoe. We sat next to her all day every day, stroking her, talking to her, washing her, feeding her, or just sitting quietly whilst she slept. She had neurological test after neurological test, including EEG's, nerve / muscle conduction tests and many others most of which we did not understand, but all of which, more importantly, were normal. She continued to be naso-gastrically fed as she still couldn't swallow, although she was managing to swallow her own saliva.

Rhona came to visit us on the Tuesday. She stayed and kept us company all day, and towards evening we took her back to Rainbow House. Rhona and I talked about the possibility of Zoe having a neurological condition and she, like us, felt that she didn't. It felt very unreal showing Rhona around the house in which we were now living, and I remember commenting on how I felt that we'd been "plucked out of a normal life and put into this strange world and that there was no indication when, if ever, we would return to normal".

The following day, Wednesday, I woke with a streaming cold and Oliver was vomiting so we stayed at Rainbow House for the day. My brother, Richard, and his wife, Hilary, came up from Sussex to visit Zoe, and Keith bought them back to the house at lunch time to see Oliver and I. They have never told me but I gather that their visit to London upset them deeply. You cannot imagine the magnitude of children's suffering until you enter a place such as Great Ormond Street Hospital and see it for yourself. Keith and I lived within this environment for six weeks. Sometimes we would sit silently, deep in thought in the Parents' Room alongside other parents who were doing the same. It was not an uncomfortable silence, but an understood silence. There was just absolutely nothing to say. There was one couple that we would frequently sit beside in the early days, each of us deep in thought. They were an older couple - we never even knew their names. One day they were there, the next they were not, and, when I asked the nurses where they were I was told that their only child, Cherie, had died during in the night. She was three years old. It was an unspoken fear of all of ours, wondering who would be next.

Oliver and I stayed away from Zoe the following day aswell. We didn't want to pass any bugs on to her but it was very frustrating being just around the corner from her and not be able to see her. Keith came back from the hospital and said that she had had a good day and that he had managed to cuddle her out of the cot for at least two hours which was excellent news. As she was no longer ventilated she did not need to be on the PICU, although everyone agreed (finally) that she did need constant supervision due to her sudden episodes. It was decided that she could be moved to a ward as long as she was 'specialied' (a Staff Nurse was allocated to care for Zoe for each shift) and so we met Lucy.

It was a Friday morning and Keith, Oliver and I arrived on Churchill Ward to visit Zoe. Lucy was on the day shift (8 am to 8 pm) and was responsible for specialing our daughter that day. Zoe was lying sleeping peacefully in her cot on an apnoea mattress with a saturation monitor probe attached to her foot. She was also in the head box as her oxygen levels had been dropping overnight, and, inspite of my staying away it seemed she had somehow begun

to develop the symptoms of a cold.

Lucy was a lovely girl - very easy to get on with and very good at her job. This particular Friday Dr Collins and her team were just beginning their ward round. Dr Collins came into Zoe's room and said that she would finish the ward round and then come back and have a chat with us. This indicated to me that she had something important to say.

We noted that Zoe's condition had deteriorated, once again, overnight and her cough was a lot worse. At 9.30 am Keith took Oliver to the Play Centre and later Dr Collins returned and, leaving her team behind she asked us to follow her down the corridor to an empty Staff Room. Lucy came with us and we all sat in a circle waiting to hear what Dr Collins had to say. She was very honest with us and admitted that every neurological test to date had proved normal but, despite this, she had a very strong feeling that there was something seriously wrong with our daughter. She had no grounds to think this, just her instinct, but she said she thought it, "very unlikely that we would ever be taking Zoe home". She added, "I think you know what I mean by that, Mr and Mrs North". She went on to explain that she felt the problem lay in Zoe's brain stem where all the vital functions of the body (such as breathing) are controlled. She said that she hoped she was proved wrong, but if she was right, she emphasised that there could be nothing that anyone could do for Zoe. She added that this 'chat' meant that they were not giving up on Zoe - she would continue to be resuscitated until a definite diagnosis had been reached. And if her present condition deteriorated further then she would be returned to the PICU later that day.

Keith and I were pretty shocked by this news, especially as we had no positive facts to grasp to make it all the more true. Keith sat white-faced crossing and uncrossing his legs during the conversation, and I sat very still, conscious of how I was acting and knowing that all eyes were on us. I fleetingly thought of all the similar conversations I had sat in on in my nursing role, and that now, finally, I knew how the patients and their relatives felt being dealt such a cruel blow.

Don't get me wrong, I was pleased that Dr Collins was being honest with us, but all the time that no-one in authority spells out the possibility of death to you then you deny that it can happen simply because no one has told you. Now that we had been told we suddenly seemed to think that Zoe's death would be imminent, although her actual condition itself hadn't changed, and she was still the same as she'd been over the last six weeks.

We didn't cry until Dr Collins and the others had left the room and we were alone. Both of us immediately thought of Oliver and what we would tell him about the sister he adored so much. We decided to try and broach the subject with him that day, feeling that it was better that he was prepared should anything happen to Zoe soon.

We went back to Zoe's room, but, try as I might I just couldn't stop the tears. Poor Lucy, I had only just met her and I couldn't stop crying! I remember asking her if she knew of any books that explained death to children and she promised to find out for us. My mind went back to the time our friend Gill's first husband, Mike, died of leukaemia. Gill was left with three year old Amy and six year old Tim. Her explanation to Amy was that, "Daddy has gone to the stars", and several weeks later, aboard a flight to France Amy had the passengers in tears when she looked out of the aeroplane window, saw the stars, and loudly told everyone that her Daddy now lived there. Thus, that morning the concept of Zoe's star was born in our minds.

We decided to collect Oliver from the Play Centre at lunch time and all go back to Rainbow House for some lunch and have a break from the hospital. There we tried to talk to Oliver, saying that Zoe might not be returning home with us when we eventually went, as, she might be going to join 'Pops' in the stars. (Keith's dad had died two years previously and Oliver remembered him and recognised the fact that he was no longer around.) He started crying and shouting, "No No NO, Zoe IS coming home with us. She is". He wouldn't hear any of it, and it seemed such a shame to continue upsetting him with information that wasn't absolutely definite. After all, no test had proved anything - Zoe may still be diagnosed, treated, be well, and continue to grow up. No one knew anything for sure, so we decided not to mention the subject again to Oliver until we knew for certain.

The rest of that day was very emotional. It had now been spelt out to us that losing Zoe was a real possibility - no one had said it before, it had been in our minds but no one had told us, and now that the doctors agreed, this confirmed our worst fears. We wanted so much to disbelieve Dr Collins, after all, she had no definite proof.

My overriding concern was that everyone would now not be so alert with Zoe, and, that despite Dr Collins' reassurances Zoe would now be considered a hopeless case. How wrong I was! Over the next few days it seemed that all the stops were pulled out and I think that everyone was of the opinion that anything was worth a try.

Continuous naso-gastric feeding was commenced to see if this improved Zoe's cough. In the past a bolus feed via the naso-gastric tube had usually preceded a breathing problem. Maybe, I thought, because her stomach was so full of milk when she coughed, some came up from her stomach and entered her lungs causing her to stop breathing? It was a possibility that I felt was worth considering.

Three infusions of a drug called Sandoglobulin were given over the next three days. This is a preparation which contains antibodies to viruses, and it was thought that this might help Zoe if she had some sort of auto-immune deficiency.

Zoe was still very poorly although her condition had not worsened. On the Saturday (February 11th) she momentarily stopped breathing several times and required bagging. During one of these episodes both Lucy and I noticed some milk trickling out of her nose. It seemed that my theory could possibly be true - milk was refluxing up from her stomach and causing her to stop breathing. The doctors were informed and the possibility of jejunal feeding was mentioned. This would involve passing a longer, thinner tube down through her stomach and duodenum and into the next part of the digestive tract, the jejunum. It would mean that her stomach would remain empty and the milk would, therefore, be absorbed from her small intestine. Keith and I were in favour of trying anything, so Lucy passed the tube slowly into Zoe's jejunum. An X-ray established that the end of the tube was sitting in the correct place and milk feeds were started the following day, Sunday.

It was also noted that Zoe always seemed to be rigid whenever she was experiencing difficulty in breathing. The possibility of her fitting was also discussed and the doctors decided to try an anti-convulsant drug to see if this helped. The drug, called Epilim, was started on the Saturday and was given in liquid form via the naso-gastric tube. Poor Zoe now had two tubes sticking out of one of her nostrils, a naso-gastric tube and a jejunal tube, and she also needed continuous oxygen which was also given via nasal cannulae. All of the

tubes didn't bother her at all and she never tried to pull them out.

By Sunday afternoon Zoe was bright, alert, and smiling non-stop! She was miraculously improved, but what was it due to - the epilim, the jejunal feeding, or the sandoglobulin? Or had the cold just got better? I didn't really care what had caused the improvement, I was just pleased that she still had the ability to 'pick-up' and improve despite the doom and gloom that we had heard just two days previously. I was very keen for Sunday to be over and to see Dr Collins's face on Monday morning when she saw our daughter. She would then realise that she had got it all wrong. Of course she had never seen the 'well' Zoe, and when she did she wouldn't think the worst anymore.

This was wishful thinking on my part. I did not want to believe that Zoe would die. I knew that she was seriously ill and that she would probably need a major operation (such as a tracheostomy) and probably 24 hour a day care for the rest of her life, but, at this stage I was convinced that she would live and we would adapt our lives accordingly. After all, there seems to be a treatment for everything these days - why should my daughter's illness be any different?

That night (Sunday) Zoe was to have an overnight investigation known as a Sleep Study. Basically, it was to see if, whilst she was asleep, she forgot to breathe. She was to be taken to another part of the hospital for this, and while I bathed and put Oliver to bed at Rainbow House, Keith accompanied Zoe to her new cot and new nurses. I was concerned that she was, yet again, going to the unknown. The nurses didn't know her and she didn't know them. Would they watch her so carefully? Did she now look so well that she was deemed to be out of danger? I worried but said nothing, and just hoped that nothing untoward would happen overnight.

Keith and I had gone to bed at Rainbow House about 11 pm that night. At 3 am I was suddenly woken by our pager urgently bleeping. My heart was racing as I tore down the two flights of stairs to the telephone in the kitchen. Keith followed me, and all I could say on the way down the stairs was, "I knew they wouldn't watch her - I just knew it!". I was shaking all over when I finally got through to the Sleep Study Unit on the phone and I tried to make the Staff Nurse understand me. "I'm Zoe's mum. What is wrong?". I kept repeating it but no-one seemed to know. According to them Zoe was sleeping soundly. It turned out that the batteries in our pager were running low and so the alarm had been a warning to us to replace the batteries! Needless to say we didn't get any more sleep that night!



A new family had moved into Rainbow House a few days before. They were Karen, Tony and their three year old daughter, Emma. Emma was a very pretty blonde, curly haired girl with a lovely smile. She and Oliver played well together. Emma's younger sister, Kendal, was a patient on the Cardiac Wing at Great Ormond Street Hospital.

One evening Keith and I were cooking our meal downstairs in the kitchen and Oliver and Emma were playing in the playroom, the next floor up. Oliver called downstairs that he wanted a 'wee', and I replied, "You know where it is, go on up". The toilet was up a further flight of stairs. We assumed that he had gone up, used the toilet, come down and carried on playing. He hadn't. Later, urgent cries of "Mummy, help!" came downstairs. I ran upstairs, but the playroom was empty, the shouting was coming from further up. As I mounted the bottom step I could see rivers of water trickling down from the top. When I

reached the toilet the sounds of running water and screaming was deafening. My shouting added to the din! Emma was sitting on the floor in inches of water, and Oliver was trying to walk out the door but kept slipping over. Both were soaking wet. Apparently they had both had a 'wee' then tried to wash their hands. Not being able to find the plug, they had used toilet paper to block the plughole and then turned the taps full on and been unable to turn them off! Water was cascading over the top of the sink and out the door and the whole scene was quite a picture! The rest of our evening was spent mopping up and trying to dry the carpets before Rose came in the next morning!

Zoe had now been in hospital for seven weeks and two days and we had all been in London with her for two weeks. Our home seemed very far away and part of another life altogether.



Following Zoe's excellent day on the Sunday, by the Monday she wasn't well again. She smiled a lot and was happy, but she needed bagging at least six times throughout the day. A repeat EEG was normal so the Epilim was discontinued. The Registrar, Jean-Pierre, mentioned that one of Zoe's kidneys felt enlarged and that, possibly, there was a mass on it. Nothing surprised me anymore - time had taught me not to worry about anything until it had been proven. Whereas at Brighton, during the bronchoscopy I was busy working everything out in my mind about the tracheostomy equipment in the house etc. I now adopted a 'wait and see' policy. An urgent ultra-sound was organised and Lucy and I accompanied Zoe to the X-ray Department and we watched the scan. Luckily Zoe didn't stop breathing in the department or the corridors. It was my nightmare that we would have to stop and bag her in a public place with everyone watching, but thankfully the expedition was completed uneventfully. The ultrasound was normal. There was no mass.

The next day we had three lots of visitors. Zoe's condition had improved and she was out of her cot for most of the day. Our first visitors were our friend Kate and her daughter, Victoria, who had travelled up on the train from Worthing. Oliver and Victoria had been born two days apart in the same hospital so Kate and I met in the Maternity Ward and remained in touch (although we knew of each other before this as our husbands' had worked together). It was a lovely surprise to see them both and we spent a couple of hours catching up on all the news and amusing Zoe.

I was taking very seriously the 'milk in the airways' theory and I decided that I would try and keep Zoe upright all day to see if this reduced the number of episodes that she had. I sat, or walked around with Zoe, her chest up against my chest all day and her coughing dramatically ceased. I really thought we were beginning to get somewhere.

Our next visitor was Karen, our friend from Burgess Hill. She had also travelled up on the train and we had another long chat. Around 3 pm my friends, Rhona and Jen, from work arrived, and Karen left to catch her train home. Rhona and Jen told me all the news - it was good to hear about life at the hospital, even if I wasn't a part of it, temporarily. They brought with them so many good wishes from the staff and patients, it seemed that everyone was thinking of us back in Worthing.

While Rhona and Jen were with us Dr Collins and her team came to see us on the ward round. Dr Collins agreed that Zoe was, indeed, a different girl to the one that she'd seen the previous Friday. She wanted a particular test, called

a Tensilon Test, repeated as she wanted to see the results for herself. This test indicates whether or not the patient has a condition known as Myasthenia Gravis - a disease which is characterised by weakening muscles, difficulty in swallowing, coughing, double vision and drooping of the eyelids. The test involves intravenously injecting a drug and watching to see if any improvement occurs in the patient. The test was once again, negative.

Now that Zoe's condition had improved Dr Collins wanted the other investigations to continue. She wanted another lumbar puncture performed and another brain scan to see if there were any changes from the previous one. As she felt that the problem was probably progressive there was no time to lose - the testing must begin again in earnest. Time was running out.

Soon after Dr Collins saw us we were visited by two clowns who tour the hospital weekly and cheer up all the children (and adults!) with their amusing antics. Their names were Dr Ki-Ku and Dr Leonardo and they were extremely funny. They captured Oliver's attention with their bag of tools and made him a balloon sausage dog. It was a very entertaining five minutes!

Rhona and Jen came back to Rainbow House with us that evening. Before we left Zoe we asked Lucy to raise the head of her cot by 45 degrees so that even when she was laying down she was still fairly upright.

Back at the house we ordered a take-away pizza which was duly delivered half an hour later and quickly devoured. Rhona and Jen met our housemates, Ros and Bill. Sarah, their daughter had, by now, been diagnosed following a lymph node biopsy as having Acute Lymphoblastic Leukaemia and was a patient on Robin Ward.

Before my chums left us that night they gave us an envelope, only to be opened after their departure. It contained a card full of messages from all our friends at Worthing Hospital and a wad of money. Living in London was expensive - for convenience we had eaten out a couple of times. It wasn't a case of, "Let's get dressed up and have a nice meal out in a London restaurant". It was more a case of leaving the hospital, drained and exhausted, with a tired Oliver in tow, and not being able to face the thought of getting back to the house to start cooking. So we would pop into the Pasta House on the way and eat a quick meal. We also still had our house to run back in Worthing, with our mortgage and bills to pay, so the money would come in very useful and we were very grateful.

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The following day, Wednesday 15th February, was an excellent day for Zoe. She had been referred to the Gastro-enterology team headed by Consultant Surgeon, Mr Pierro. He came that afternoon and examined Zoe and agreed that gastric reflux was, indeed, a possibility, and could be causing Zoe's symptoms. I asked him if severe reflux could hyper-extend the neck, as in Zoe's case, and he said that it could, he had seen it before in other children. I was getting more and more hopeful. Mr Pierro stressed to us that reflux might only be a small part of Zoe's problem, but, if it was proven then he was prepared to perform an operation on her to stop it occurring. He explained that he was going on holiday for one week and would leave the investigating to his Registrar. Zoe would need another pH study, and if this indicated reflux then Mr Pierro would operate on her on the Wednesday of his return. This would be the 1st March.

We had Zoe out of her cot, and upright, all day and she didn't require bagging at all, or cough much. On the rollercoaster of hope we were at a high

point. We were finally getting on top of it! It was a happy day, thinking that a simple idea such as keeping her upright could make her so much better, and that it all could be due to reflux which could be easily dealt with. I spent that evening on the phone at Rainbow House telling all our callers that Zoe was so much better and that we were finally on the UP.

Our friends Roy and Col came up to see us that day, bringing Katie and Peg. Roy took some lovely photos of Keith and I with Zoe.

We came crashing down to earth with a bang the following day. We had arrived on Churchill Ward around 9.30 am and said "Good morning" to Zoe who was lying awake in her cot (at 45 degrees) looking around. She gave me the most beautiful beaming smile, and Lucy told us that she had had an excellent night. My mum and dad were due up that day and I was pleased that they would see her looking so well.

Lucy popped across the corridor to get something and I picked Zoe up out of her cot. Oliver came over and said "Good morning" to his sister. Suddenly Zoe gave a little cough and she was gone. Completely lifeless in my arms, and that horrible horrible blue colour. I threw her back on the bed and shouted for Lucy who came immediately. Zoe was not breathing and had no cardiac output. Keith and I then stood back and witnessed our own daughter's 'Crash Call'. Suddenly the room was full of doctors and nurses and, as the Anaesthetist was about to intubate Zoe we were ushered into the nurses office across the corridor. After a few silent minutes we heard Zoe crying. They had got her back!

We were asked if we wanted to see Zoe, which, of course, we did, and she was struggling to breathe just as she had done at Brighton. The team were deciding whether or not she should be ventilated as they said she was now 'holding her own', but I loudly insisted that this was not 'her'. This was not how

she should be - she was still not quite right. The urgent blood gas results convinced them that this, indeed, was true, and they agreed to ventilate her. We were again ushered away while this was being done. Keith took Oliver down to the Play Centre and met my parents in the lift on his way back up.

A nurse kept returning to us to inform us of Zoe's condition and apparently during the intubation Zoe had suffered another cardiac arrest. At one point, the Anaesthetist reported, the bronchus was completely obstructed and the tube could only be inserted into her lungs when the blockage cleared, which it did spontaneously a few seconds later.

Once Zoe was ventilated we were all allowed to see her quickly before she was taken to the PICU again. We stayed on Churchill Ward and voluntarily helped to clear up the room. There were suction tube wrappers and papers everywhere which had all been thrown down in the panic. I couldn't believe that we were helping to clear up after our daughter's cardiac arrest but, at least it kept us busy until we could see her again.

We then had a cup of tea and a chat with the staff. Lucy had taken Zoe to the PICU and had not yet returned, but Steve, the Senior Staff Nurse, and Tess, a Staff Nurse from New Zealand stayed and talked to us, largely recounting the events of the last hour. Then they rang through to PICU and we were allowed to go over.

Zoe was off the ventilator when we arrived and breathing well. She had some nasal cannulae giving her oxygen and a 'drip' in her foot giving her fluids. She was very poorly now and her chest was sounding very 'bubbly' again. The PICU was very short-staffed that day so Lucy had volunteered to stay there and care for Zoe (which was very brave of her as she wasn't ITU trained, but all the appropriate staff were nearby should she need them).

Dr Mok, one of the Consultant Intensivists, came over to talk to Keith and I soon after we arrived on the Unit. She stressed to us that Zoe's lungs were now in very very poor shape. She showed us Zoe's chest X-ray which she said was a complete 'white-out'. This could be due to a variety of conditions, she explained, such as aspiration of milk into the lungs, pulmonary oedema, sudden infection or heart failure. As no-one knew which condition Zoe had now developed Dr Mok said that she was treating her for all of them. She was having intravenous antibiotics, diuretics, and nothing further orally until her condition improved. She also explained to us her views on this morning's events, although she was not able to give us reasons why the events occurred. She felt that, for whatever reason, Zoe's airway went into spasm, closing it completely. As no oxygen was, therefore, getting into her lungs, neither was her blood being oxygenated, or her organs, hence that horrible blue colour. Her heart suffered, due to the lack of oxygen, and slowed and slowed until it eventually stopped. When Zoe's heart temporarily stopped and she had, effectively, died, then all the muscles in her body relaxed, including the airway - which then allowed Zoe to start breathing again and, therefore, be resuscitated.

It was too much to take in all at once. I don't think we fully understood all this information for several days. All we really knew was that she was now very ill again and all the previous hopes had been abandoned.

I began to think about my imminent return to work. This was my last week of Annual Leave for the year and I was due back at work in three days time. The last thing on earth I could envisage myself doing was working efficiently. I decided that I must ask if there was anything that could be done for me - going without pay was out of the question as we had no savings to pay the mortgage, but I knew I would not be safe to return to work. I went down to the

payphones in the main entrance of the hospital and rang Clare, the Sister of the ward where I work. She assured me that I shouldn't worry - she, my Nurse Manager, Angela Bailey, and the Clinical Director of Medicine, Dr Bull, were sorting everything out. I hated asking to be off work, but under the present circumstances I felt that I had no choice. I hoped everyone understood.

Keith and I were allowed to have Zoe out of her cot that evening. We took turns to cuddle her amid all the wires and tubes. She was attached to a heart monitor, had a drip in her foot, the oxygen saturation probe on her other foot, the naso-gastric and naso-jejunal tubes coming from her nose, and the nasal oxygen cannulae going into her nose. Getting her out of the cot was a very complicated business and she showed no response when we finally had her in our arms. She looked, and probably felt, very very ill.

The following day, Friday, Zoe's chest was slightly better. She was still too ill for any smiles, she slept a lot and looked around for short periods when she was awake. Two more of our friends from my work visited us that day, Jane and Lydia. They were in London for a Study Day and called in on us on their way home. Their stay was brief but it was lovely to see them both. Soon after they left us another friend of ours, Pip, arrived. She lives in Bromley and we hadn't seen her since Christmas when she came to our house to meet Zoe for the first time. I had been to school with Pip many years previously and although we had always kept in touch with each other, we hadn't actually seen each other much.

This particular evening we were waiting for Zoe to have another brain scan. As the Scanner was fully booked we had to wait for a gap and she would be slotted in as an emergency. We collected Oliver from the Play Centre, and, by 6.30 pm we had run out of ideas for entertaining him. There was still no news of the time of Zoe's scan so Pip and I decided to take Oliver back to Rainbow House and start preparing the dinner. Keith remained with Zoe. We knew that she would be sedated and ventilated for the scan and that, afterwards, while she was still sleepy, the doctors would perform another lumbar puncture. One of the theories currently under discussion was whether the mycoplasma organism had entered Zoe's cerebro-spinal fluid (CSF) and was causing some of her symptoms.

Keith returned to Rainbow House an hour later and said that Zoe had just begun to be scanned when he had left, so we quickly ate dinner and Pip kindly offered to mind Oliver while Keith and I went back to the hospital. When we got there Zoe had just returned from her scan and was heavily sedated and ventilated. The room was once again filled with the sounds of the machinery that was breathing for her. We were eager to know the results of the scan as soon as possible, and, no sooner had we asked - the doctors came and told us that it was once again "all normal!". We were elated once again. Her brain WAS normal, just as we had thought. But then what could it be that was causing such severe symptoms? We opted for the mycoplasma in the CSF, or a problem with her respiratory tract. I left Keith with Zoe, assisting with positioning her for her lumbar puncture, and went back to relieve Pip of Oliver. It was getting late and she had to get back to Bromley, so I ordered her a taxi and arranged to see her the following week.



On the Saturday (February 18th) we arrived on PICU around 9 am and we were ushered out again because of the Consultants ward round. A team of Intensive

Care doctors toured the Unit twice a day, morning and evening, and saw and discussed every child. No relatives were allowed to be present whilst the doctors were discussing their child. This is due to the fact that many conditions may be discussed at the bedside and parents may mishear or mis-understand the information and then worry unnecessarily. Keith and I were very lucky in the fact that Dr Mok or Dr Tasker always came back to us afterwards and kept us up to date on their ideas of what might be wrong with Zoe. We knew that everyone was doing their best, and that they were telling us all that they knew.

This particular morning Dr Mok returned at the end of the round and told us that the lumbar puncture had showed nothing abnormal. The CSF was clear. Another theory out of the window!

Following the scan and lumbar puncture Zoe's sedation had been lightened over night and by the morning she was breathing for herself again and was, therefore, taken off the ventilator. She was, once again, moved to a three bedded bay, alongside her old cot space. She was in Peter's old cot space and I, in conversation, asked one of the nurses how he was getting on. I was told he had died a few days earlier.

The medical staff decided that Zoe should begin milk feeds again. I was unhappy about this as I could envisage the whole process starting again, but, who was I to stop them? They had to try and find out their answers. The jejunal tube hadn't been used for a few days and, by now, was blocked. It was removed and a naso-gastric tube passed in it's place, despite my lack of enthusiasm. Zoe could then, at least, re-start her medication via the tube, and, if possible a naso-jejunal tube would be passed later. It took several attempts to pass the naso-gastric tube and Zoe, apparently, at one stage, turned black and needed bagging and extra oxygen. We had been asked to go to the Parents' Room so we had not seen this episode, but Tony, Zoe's nurse, told us of it afterwards.

Keith's eldest brother Ian and his wife, Imelda, visited us that afternoon, as did Simon, Rachel and Peg. There was quite a gathering in our little corner and Oliver had a lot of attention and people to talk to. We had Zoe out of her cot and she gave everyone beaming smiles. She had such long long eyelashes which almost reached her eyebrows, and when she smiled she looked very pretty. Ian and Imelda had not seen Zoe since she was few weeks old as they live some distance away from us, and I think it was quite a shock to them to see her connected up to various tubes in such an alien environment. They were also to be Zoe's Godparents.

The next day, Sunday, Zoe was moved further along the PICU into the next bay. My parents came to visit, and so did Clare, my friend who had visited us in Brighton. She came with her family but, as her husband, Michael, had a cold, he and their two boys stayed in the Playroom.

Zoe was improving every day following her cardiac arrest, and, this particular day she was bright and smiling. There had been several attempts to pass a naso-jejunal tube but they were unsuccessful so naso-gastric feeding was commenced once again. After this, Zoe's cough markedly worsened and I pointed this out to anyone who would listen.

Our friends from Uckfield travelled up to see us on the Monday. I had completed my nurse training with Elaine (who was Clare's friend) back in 1979, and she and her husband Paul had a restaurant in Uckfield. They have two boys but they had left them with their grandparents. Zoe had several minor episodes that day. She needed a chest X-ray and the radiographer wanted her lying flat on her back which kept making her, momentarily, stop breathing. I would have to bag her to start her breathing again, then begin the whole

positioning process all over again. It was a trying time and I got very anxious that she would have another cardiac arrest.

Elaine and Paul stayed several hours and the chat flowed easily. Elaine, like Clare and my other nurse friends, was used to such environments so felt more 'at home' and comfortable in the situation we were in. I felt tearful when they left (as I did when everyone left us) as I couldn't help but wonder if this would be the last time that they would see Zoe. I am sure the same thought went through everyone's minds.

That afternoon Mr Pierro's Registrar came to insert the probe internally for the second pH study. This involved passing yet another tube down Zoe's nostril into her oesophagus and leaving the tip of the tube just above the stomach entrance. This probe was to measure the acidity of the liquid around it and determine whether the acidic stomach contents were slopping up into the gullet. I was very nervous, having seen Zoe turn blue during so many naso-gastric insertions and I kept telling the poor Registrar to be careful and that he would need the bagging equipment and oxygen nearby. Almost before I had finished speaking he had the probe inserted with absolutely no bother at all! He probably thought that I was a completely mad and over-reactive mother, but then he had never seen Zoe as I had seen her.

The pH study was to last for 24 hours. There was a little box attached to the external end of the probe and the readings were to be stored in this box for later analysis. On the side of the box were displayed the ever-changing pH levels. I continually watched the numbers over the next few hours and I got more and more excited as time went by. The reading was continually as low as one or two which is very acidic. We had our answer! I had it all worked out. She DID have reflux. She would have the operation and all would be well. Simple! Anyone who telephoned us that night at Rainbow House heard very positive news.



The next day, February 21st, was Keith's 42nd birthday. Several members of our family had asked him if there was anything he particularly wanted for his birthday - his only reply was that his daughter would get better and be able to go home. It was the present that we all desperately wanted.

We spent the day quietly sitting beside Zoe on the PICU. Tony, the Staff Nurse who had been caring for Zoe for the last few days was excellent. Oliver was taken into the kitchen by Pamela and more cakes emerged (with no fire bells!) and Oliver delivered the tray of fairy cakes to all the PICU staff. The pH probe was removed at 4.30 pm and sent off for analysis.

That evening before we left Dr Tasker came to talk to us. He told us of the three theories that were still being considered as to the cause of Zoe's symptoms. One was that the mycoplasma was still prevalent in Zoe's body, another was that she had a neurological condition, commoner in the Jewish population, which was causing an abnormality of her upper airway and swallowing mechanism, and lastly, that she had gastric reflux. I asked him if he thought that reflux could possibly be Zoe's only problem, and his reply was that it most certainly could. I told him of the low pH readings and he said, "Let's hope that's all it is then!".

The next day Zoe was moved back to Churchill Ward again under the care of the Neurologist Dr Jane Collins. This disturbed us slightly as we still felt that Zoe had the neurological label which she just couldn't shake off. We felt,

wrongly we now realise, that Zoe should be anywhere BUT the neurological ward. The Respiratory or the Gastro-intestinal wards would surely be more appropriate for her symptoms? No-one else agreed.

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One morning I had arranged to have my hair cut. We had now been in hospital with Zoe for nine weeks and any normal events, such as going to the hairdressers, had all been forgotten. But my hair was now too long and I had no time every morning to blow dry it and make it look presentable. I had found a hairdressers the day before, just around the corner from the hospital, and had made my appointment. At the designated time I went, armed with the pager, to have my hair cut to a 'short and easy to manage' style. The trendy young man with the scissors certainly took my request literally, and I was left with a light covering of hair, with nothing to blow dry even if I had wanted to!

It was a very strange experience being outside the hospital and doing a normal activity such as having a haircut. In and around the hairdressers other peoples lives were carrying on with, it seemed, no thought whatsoever for the hundreds of sick children just around the corner. How lucky they all are, I thought, not to be affected by tragedy and illness. I now realise that you cannot ever imagine what traumas are going on in other peoples' lives just by looking at them. To fellow clients in that hairdressing saloon I was just another person having her hair cut. No-one could tell of the nightmare situation I was in. (They did have a slight inkling that I was not totally at ease when a bleep sounded indicating the completion of a perm, and I jumped from my seat in sheer panic thinking it was the pager and the hospital needed me!)

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The following day, 23rd February, Zoe was six months old. She was rapidly gaining weight due to a high-calorie supplement that was being added to her feeds. She now looked considerably more healthy than when we first arrived in London. Keith and I accompanied her to the X-ray department for a repeat of the barium meal investigation. Every investigation she had ever had had now been repeated to see if anything had been missed.

Going to the X-ray department was quite an expedition. We took Zoe and all the resuscitation equipment on the cot. Myself, Keith, Jo (Zoe's nurse for the day), and the SHO on duty (in case Zoe stopped breathing) walked alongside. We made quite a procession as we travelled through the old corridors to X-ray.

I'm afraid my nurse / mother instincts took over that morning and I, knowing Zoe as none of the others did (apart from Keith, of course) took over and dominated proceedings. The radiographer did not like me being there, and liked it even less when I climbed on the X-ray table and began giving oxygen to a distressed Zoe, who was on the brink of yet another bronchospasm. I was past caring what anyone thought - my priority was to get Zoe back to the ward without her arresting in the X-ray department. I had seen the signs preceding an episode so many times, I just knew what was coming if they carried on, so I asked them to stop. The radiographer had some excellent pictures which did show some reflux, and I felt there was nothing to gain by trying out yet more barium or Zoe in different positions. Jo, the nurse, agreed with me and the entourage proceeded safely back to the ward. My parents were waiting for us.

Jo had looked after us all very well during the time we spent on Churchill

Ward. She was a very kind and efficient young nurse and I was, therefore, quite shocked when my mother said that Jo had approached her shortly after the X-ray trip as she thought that she had upset me by not being forceful enough during Zoe's barium meal. Such a thought was furthest from my mind. My utmost concern was for Zoe's welfare, and not who had said, or not said, what. I had not expected Jo to halt the proceedings as Jo had not seen one of Zoe's episodes. I knew my daughter well enough to know when she had had enough, so, I felt it was up to me to stop everything, which I did. I apologised to Jo for making her think such a thing, and assured her that it was not true. She was most embarrassed that my mum had told me!

Later that day another good friend, Claire, and her husband Nick came to visit us from Haywards Heath. They have three girls, who they left with Claire's parents. Claire, myself and Pip had gone through secondary school together and had remained in contact ever since. Zoe was having a very good afternoon, she smiled, chuckled, and chattered for Claire and Nick, and they were amazed at how well she seemed. I had been asking the staff all day if there was any news of the result of the pH study, but, as yet, there was none. I explained to Claire and Nick how low the readings had been, and I said that I was sure that this was Zoe's problem.



That day my parents told us that one of the houses in Worthing, near our own, had been burgled. The burglar had escaped across our garden, leaving his footprints in Oliver's sand pit. We were worried as our house had now stood completely empty for nearly a month. Keith decided that he would go back to Worthing on Friday for the weekend and make sure that all was well. Oliver and I would stay in London.

On that Friday we had a lovely surprise. I saw the face of my Uncle Alan (my mother's brother) through the glass of our cubicle. He was standing in the corridor, about to ask one of the nurses where we were. It was a wonderful surprise to see him - we hadn't been in contact with him since arriving in London, but my parents had kept him informed of Zoe's condition. He had never seen Zoe before and was, I think, shocked at all the tubes and machinery that was attached to her. To us, Zoe was having a good day (because we had seen far worse) but we forgot that, to others, it was not normal to see a baby looking as Zoe did. She was pale faced with pipes coming out of her nose and her head held back. To us, though, she was still beautiful. My Uncle Alan stayed a few hours, chatted to us, played trains on the floor with Oliver and left around tea-time.

It was promised that we would receive the results of the pH study on that Friday so we waited expectantly. After Uncle Alan left, Pip arrived. By 6.30 pm Oliver was thoroughly bored so we prepared to leave the ward without knowing the results. As we got to the lifts Mr Pierro's Registrar, whom we had waited all day for, emerged. We all went back to Zoe's room and waited for the verdict. He explained that the pH study did, indeed, show very low readings. So low, in fact, that it had to be assumed that the test was of no use - the probe must have actually been inside the stomach. "No reflux could be that severe," he told us. "The test must be repeated." It was to be Zoe's third pH study! The doctor then re-inserted the probe, as expertly as before, and as we left the ward the portable X-ray machine arrived to take yet more pictures of Zoe's chest to check the position of the probe.

The next day, Saturday, Zoe was moved along the corridor to a four bedded room at the end of Churchill Ward. Her original cubicle was needed for another patient. None of Zoe's regular nurses were caring for her that day. Instead, an Agency Nurse (who was employed by the hospital to work any shifts that were short of staff) was responsible for Zoe's care. It worried me that she was now in a main ward and that none of her regular nurses were looking after her. I hoped that the extremely high standard of care that she was used to continued. It did. Towards the end of the morning, though, I realised I didn't much care for the nurse looking after Zoe. I usually cuddled my baby whenever I liked, but this particular nurse told me to lie her back down in her cot after about an hour so that she could rest. I didn't take too kindly to being told what I could or couldn't do with my own daughter.

Now, in the same room as Zoe, was an 18 month old boy with cerebral palsy and hydrocephalus (an abnormal accumulation of CSF within and around the brain). His shunt, draining the CSF, had blocked and he was vomiting and in pain. The poor mite screamed constantly. He also had an identical twin (whose shunt hadn't blocked) and he was with his grandparents while his brother was in hospital. The boys' parents were at the hospital and we talked briefly, both of us, I think, feeling sorry for each other.

Peg, Simon, and Rachel came up that Saturday (as usual) and we sat in our new environment chatting and cuddling Zoe. I remember that she gave a particularly long and loud cough that morning, then a loud shout afterwards which made the Senior Staff Nurse, Steve, who was passing by at the time, laugh. He made some funny quip, I can't remember what now, and everybody chuckled. Zoe enjoyed all the attention and had a lovely day being walked around on Keith's or my chest. She was having full strength feeds again now and these were two hourly via the naso-gastric tube. I knew that her cough was worsening in conjunction with the feeding being increased, but generally she was much better. I hoped that the constant vigil by the nursing staff wouldn't cease now that she seemed improved, had a new nurse, and a new room.

Keith, we arranged, would travel back to Worthing that evening with Simon, Rachel, and his mum. They would take him to my parents house to collect our car, then he would go on to Worthing to check our house. He would then return to my parents house in the morning, leave our car there, and travel back to London with them in their car. So, around 6 pm they all departed leaving Oliver and I with Zoe. As he left, Keith told Zoe that she must be a good girl and behave herself.

Oliver and I stayed a while longer on the ward with Zoe, and then we left to go back to Rainbow House. It was nearly 7 o'clock and dark, and I didn't relish the thought of walking the streets of London much later than this. Once back at the house I took Oliver upstairs to bed then settled downstairs and chatted to the other families in the house. Keith rang to say that he'd arrived home safely and that it was freezing! I wrote some letters and went to bed.

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Oliver and I awoke the next morning and went down the two flights of stairs to the kitchen for breakfast. It was just after 9 am when we finished eating and I suddenly knew that I must telephone Churchill Ward. I can't explain why I wanted to, as we had never ever rung the ward before walking to the hospital before. I rang and the hospital switchboard operator tried ringing both the ward phones but they were both engaged. He told me that there had been an

emergency on Churchill Ward and could I please try ringing later. As I replaced the receiver, a bleep sounded loudly in the quiet kitchen. It came from within my handbag. The pager. I froze, then frantically began dialling the hospital again, telling the switchboard operator, "I am that emergency's mother. You MUST put me through, please". Tess, the New Zealander, answered the phone on the first ring. "I'm so sorry," she said, "Zoe had an arrest at 08.30 this morning". "Was anyone with her?" I demanded, desperate to hear that she had not been left alone. "Yes, I was with her," she said, "I was giving her a feed". It suddenly occurred to me that Zoe might be dead. "Is she still alive?" I asked. "Yes," came the reply, "but she's just been taken down to the PICU on a ventilator."

It was 9.15 am on Sunday 26th February. Keith was due to arrive at my parents house in half an hour so I rang and left a message for him. They would all leave Haywards Heath as soon as he arrived.

Then Oliver and I ran all the way to the hospital, through the deserted Sunday morning streets. We ran and ran, and when Oliver couldn't run anymore I picked him up and carried him. I told him that we must get there very very quickly as his sister was suddenly not very well. I was dreading what I would find when we got there - especially as it was just Oliver and I. We arrived on the PICU and ran straight over to a cot that was surrounded by doctors and nurses. There was Zoe, sleeping peacefully, on a ventilator. We were asked to wait in the Parents' Room until they had finished sorting her out.

The Parents' Room was empty so Oliver and I sat down. I was breathless from so much running. Oliver patted my hand and said, "Don't worry Mummy, it will be all right". Then he got me a cup of water from the tap in the corner of the room. I was willing Keith to hurry up. It was amazing that we had spent all these weeks with Zoe in London and the only morning that one of us was missing she has another cardiac arrest. It was unbelievable.

As I calmed down from the initial shock I began to think. Yet again, this episode had occurred during a feed. I was absolutely convinced that feeding was connected to her problem and I was adamant that I wanted Zoe to have nothing further into her stomach until a cause for all these episodes had been found. She had arrested twice now and time seemed to be running out. They had to find out what was wrong with her, and soon - we might not be so lucky next time. A nurse came to update us on Zoe's condition and I told her of my thoughts. She agreed that there did seem to be some connection between the episodes and feeding. I asked her how much the parents wishes were taken into consideration in such instances and she assured me that my views would be heard.

I was allowed to go in and see Zoe, who was sleeping on her side with a ventilator tube protruding from her nose. The naso-gastric tube had been ripped out in the panic of the arrest, as had the pH probe (which had remained in all night despite the test finishing at 7 pm the previous evening). I hoped that the answers inside it could be salvaged.

Zoe was not sedated, and was mostly breathing for herself - the ventilator 'kicked in' every now and then. Luckily I had grabbed my camera in the rush to leave Rainbow House, and now I asked the nurse if I could take a photograph of Zoe, just incase she died before Keith arrived. I thought that the nurses would think this request rather odd, but they didn't seem to at all. And, in fact, I am glad that I did take the pictures of her as, sad though they are, they are all part of how we remember her. I told the nurse that I would show Zoe the picture when she was older, just to remind her what she had been through.

One of the members of the Crash Team (a team of trained staff from the PICU that attend all arrest situations within the hospital) came over to talk to me. She had also been present at Zoe's previous arrest, and she told me that as soon as Churchill Ward came up on her pager she just knew that it would be our Zoe. She was heavily pregnant herself, and I wondered how it must feel for her to be resuscitating all these babies when the birth of hers was so imminent.

Keith, Mum and Dad arrived about 11 o'clock. Oliver and I were waiting out in the corridor for them as the doctors were with Zoe. I told Keith what had happened, and when we were called back he and I went over to Zoe's cot. She had just 'extubated' herself (pulled the tube out from her nose) and was lying awake just looking around. She took one look at her dad and, once again, gave the most enormous smile! I couldn't resist taking another photograph of her, smiling broadly, only five minutes after coming off a ventilator.

Mum and dad came in and saw Zoe, then took Oliver out to the park across the road. Keith and I, once Zoe was sound asleep, went back over to Churchill Ward to thank them for their prompt actions that morning, and to collect the rest of Zoe's belongings. The staff were still clearing up the ward and re-stocking the crash trolley. I saw Zoe's nasal oxygen cannulae lying on the floor where her cot used to be. They were full of milk and it was trickling out on to the floor....

As I took all of Zoe's sleepsuits out of her locker the mother of the twins came over. She had been asleep on the floor by her son's cot that morning and, so, had seen it all happen. We told her that Zoe was, once again, smiling, and that, by now, we were getting used to this pattern of events! She probably thought us quite blasé about the whole business!

Tess came up to us and greeted us both with a big hug. She recounted the happenings of the morning and then apologised if our daughter's first word turned out to be "SHIT". Apparently all that Tess could say during the entire Crash Call was "Shit, that doesn't fit!" and "Shit, I've dropped it!" or, "Shit, that's not long enough!" etc. etc. Even on that dreadful morning we still managed to have a laugh with those wonderful staff on Churchill Ward.

Unbelievably, Zoe remained alert and smiled frequently for the rest of that day on the Intensive Care Unit. She could roll herself over from one side to another, something she had been doing for a few weeks now, and she could pick up and grasp her toys, taking them to her mouth to suck, along with her favourite two fingers. All indications, we felt, that she was continuing to develop normally. Her cough was back, much worse due to the aspiration of milk into her lungs that morning. The staff seemed to have taken heed of my comments (or, maybe, they had thought it best themselves) and Zoe was to have no further milk until she had seen the surgeon, Mr Pierro, on his return from holiday the following day. A decision would then be reached about her operation.



Victoria, the girl who had had the brain haemorrhage, was now in the bed next to Zoe's cot. She was still ventilated and deeply unconscious. Her condition had not changed in the last few weeks. Tracey and Mark would sometimes sit with Victoria on their laps reading stories out loud to her, waiting for some indication that she could hear them, or a flicker of recognition. None came, but their patience was infinite.

There was a portable music centre in the PICU that could be wheeled around and plugged in beside individual beds allowing the children to listen to music. Victoria's classmates had recorded their school assemblies and concerts and these tapes were played to her over and over again in the hope that she would show some response. There was also a selection of music and story tapes belonging to the PICU and the staff would play these quietly to the ventilated children to try and stimulate them. (The sense of hearing is very often still present even if the patient is unconscious.) There was one particular tape, "Twinkle Twinkle Little Star" which seemed to be played over and over again. Hearing those songs, sitting beside Zoe on the PICU became a regular feature of our days. Once or twice I began to sing along to an awake Zoe, only to stop, my eyes watering, when I realised the words I was singing - "Twinkle Twinkle Little Star, How I wonder what you are. Up above the world so high, like a diamond in the sky..."



Monday 27th February heralded the end of Mr Pierro's holiday, and one of his first jobs, it seemed, was to see Zoe. He arrived on the Unit soon after 9 o'clock, just as we were returning from the Parents' Room following the PICU doctors ward round. Mr Pierro said that he was very sorry to hear of the weekends events, and he asked us to follow him to the Relatives' Room for a 'little chat'.

Mr Pierro explained that the pH study did show some reflux. The episodes of high acidity had been infrequent, but, when they had occurred they were prolonged, indicating that Zoe was indeed experiencing oesophageal reflux which was, maybe, causing some of her symptoms. He stressed that the reflux was probably only a small part of Zoe's problem, and that there was likely

to be more that was wrong with her. "I don't guarantee that this will be the end of her problems, Mr and Mrs North, but at least we have proved that this is happening and we can deal with it. I feel it is severe enough to warrant an operation." He went on to explain the operation itself, and then we signed the consent form which would allow Zoe to have a "Fundoplication (Nissen's) and insertion of gastrostomy tube". The operation would take place in two days' time, on Wednesday 1st March. It involved, simply, tying the top of Zoe's stomach so it would allow milk, and later food, to go down, but nothing could come up. A, hopefully, temporary gastrostomy tube would be inserted into Zoe's stomach and this would remain in until a cause for her inability to swallow had been found and treated. The operation meant that she would never be able to vomit - a small price to pay, we thought. For Keith and I it was a start. At last we seemed to be beginning the treatments as opposed to just carrying on with the investigations.

Wednesday just couldn't come quickly enough for me. Zoe had several episodes where she had difficulty breathing that Monday. Her cough had definitely worsened since the previous day's arrest and so I blamed the episodes on the increased secretions as she was no longer having any milk. Looking back I always found a logical excuse for everything! Mr Pierro had agreed that since reflux was indicated, Zoe should have no further milk until after the operation.

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Tuesday 28th February was a very busy day for us. We were expecting lots of visitors of our own to arrive, and Princess Diana was also coming to certain parts of the hospital to meet the children, their relatives, and the staff. She was scheduled to visit the Play Centre, which Oliver had attended for the last six weeks, and he was one of the children chosen to meet her. That morning he had, of course, woken with a streaming cold!

Security was tight as we entered the hospital that day. Two police officers were standing outside the main entrance under the covered walkway leading to the hospital doors. They bid us a "Good Morning," and Oliver looked at them in amazement. All the emergency services were his heroes at the time, and seeing real policemen so close just made his day! They were very friendly and picked him up, sensing his wonder, and one of them put his hat on Oliver's head. Camera already in hand, I managed to capture the moment!

Inside the hospital there seemed to be an air of excited anticipation -

cleaners were cleaning corridors that were already clean, and everybody seemed to be walking fast and talking into mobile phones. We all went up to see Zoe, then Keith and Oliver left to go to the Play Centre. Each child was allowed to be accompanied by one parent when he / she met Princess Diana. I stayed with Zoe, who had had a good night, was awake and looking very well. She had rosy cheeks and was getting quite a lot chubbier. She smiled and chattered to me, fluttering her long long eyelashes. She really was very beautiful.

The window of the Parents' Room looked out on to the hospital's Main Entrance, so, at the designated time I was able to look out and see Princess Diana emerging from her car. It was a moving moment, seeing her coming to the hospital to give us all support. I still couldn't quite believe that I was there - in the Intensive Care Unit of the best children's hospital in the world with our daughter who was so seriously ill. Keith and Princess Diana exchanged a few words about Zoe that morning in the Play Centre, amid the press camera bulbs popping, and Oliver was privileged enough to appear in that night's late edition of the Evening Standard, the following day's Daily Express, and the following month's Hello! magazine! It was a bit of light relief for us all.

Zoe was having a good day, her last before surgery. Dr Mok came by and chatted to me. She told me not to get my hopes too high as she was sure that Zoe's problems would not end with her operation. She still felt that our daughter would require a tracheostomy, at some stage, to help her breathing.

Mid-morning my friends from work, Rhona and Jane, appeared, and from that moment on activity around Zoe's cot was constant. Mr Pierro arrived to give Zoe a final check over before her surgery, and he, once again, commented that the operation might not solve all her problems.

At 11 o'clock I took Rhona and Jane to the Parents' Room and we watched Princess Diana leaving the hospital, shortly followed by the arrival of Oliver and Keith on the PICU excitedly telling us of her visit. We brought some sandwiches from the Peter Pan Cafeteria and settled down in the Parents' Room to watch the visit on the television lunch time news. I then caught up with all the news from work!

When we returned to Zoe she was sleeping. Kevin and Ingrid arrived. We had spoken to them on the phone several times since our arrival in London but it had been difficult for them to visit. It was good to see them. Ingrid bent over to kiss Zoe and began to cry. I put my arm around her shoulders and said, "Don't worry, Ingrid. She's having a really good day. She's fine". I hoped with all my heart that she was.

The next person to join our gathering was our friend from Worthing, Tony. He was in London on business. Keith and I had both known Tony for several years before we met each other. Previously Tony had been in the Ambulance Service, but he now works for a very reputable and well-known undertakers in Worthing. He had come to London to collect a body from another hospital, and thought that he would call in to see us. His stay was brief, but thought provoking, and I think both Keith and I made unspoken decisions that day.

Rhona and Jane left us as they wanted to visit a London book shop, so Keith and I spent the afternoon beside Zoe with Kevin and Ingrid. I had Zoe on my lap for most of the afternoon. She still had many pipes and tubes coming in and going out of her. She had an intravenous infusion, and this was going into one of her scalp veins. The actual site of her infusion was covered by a gallipot to protect it - it looked rather odd stuck on the side of her head! She, bless her, was oblivious to it all and nothing could stop her smiling all day. The clowns came to visit and Zoe gave one of them such a quizzical look which was captured on camera. Many photos were taken and we were all very relaxed. A tired Oliver returned from the Play Centre with his face painted as a clown (runny nose and all!). We tried to keep him away from Zoe to save passing on his cold.

We fell into bed that night excited, but nervous about Zoe's operation which was to be the following day. Maybe, just maybe, we would be extremely lucky and this surgery would end all our problems.

MARCH

When we woke it was Wednesday 1st March - Zoe's big day. Keith and I spent the morning beside her, and Oliver was at the Play Centre. At 2 o'clock I escorted Zoe and her nurse, Shelagh, to the Anaesthetic Room. As Mr Pierro entered the room Zoe was given some gas to make her sleepy and I said my goodbyes and kissed her. I was not in the least bit tearful - I was elated - we were finally beginning Zoe's treatment. After months and months we had found something that was wrong with her, and now it was going to be corrected. Keith was at the Play Centre so I went back to the Parents' Room and wrote a few letters while I waited for Zoe's return.

She was wheeled back to the Unit about an hour later. She was breathing on her own and not ventilated, which was good news. The Anaesthetist told us that the operation had gone well. A blood transfusion was going into a vein in Zoe's right arm. Apparently she had been anaemic before surgery so was being given a 'top-up' transfusion. She still had her scalp drip which was giving her fluids and also some drugs to control any pain. The anaesthetic had made her very relaxed and her usually hyper-extended neck was now looking normal and her chin could touch her chest.

I was allowed to give her floppy little body a 'post-op' wash soon after she came back from the operating theatre. I was very gentle in case anything hurt her. As I washed her I told her how brave she was being and that Daddy and I were very proud of her. I told her that all she had to do now was get over the operation and hopefully soon we could all go home.

Shelagh looked after Zoe, and us, excellently. She was a quietly spoken nurse who instilled confidence in us as soon as we met her. She monitored Zoe constantly and carefully. A small rubber tube (the gastrostomy tube) emerged from Zoe's tummy. Shelagh freely chatted to us as she went about her work which helped to pass the time.

Early that evening we left the sleeping Zoe and went back to Rainbow House to put Oliver to bed. We were feeling very optimistic about the future. Zoe had had the first treatment on the road to her recovery - hopefully now she would not have any further breathing problems as her stomach contents could no longer be regurgitated into her lungs. Our optimism was short-lived.



Oliver was not feeling very well with his cold, and he started to sound slightly wheezy as the evening progressed. Our GP at home in Worthing would not label Oliver 'asthmatic' at the young age of three years so all we knew was that he had a tendency towards asthma. He had given us a bottle of Ventolin syrup for Oliver when he had sounded wheezy several months earlier, and luckily I had brought it to London with us. I gave him a couple of spoonfuls of Ventolin and got him ready for bed. He lay on the settee in the lounge watching a video while Keith and I prepared our dinner downstairs in the kitchen. We had just sat down at the table to eat when the telephone rang. Another parent answered it and called us. Keith went to the phone. It was the PICU saying that Zoe had stopped breathing. She hadn't taken long to start again, but they felt that they should let us know. If it happened again, they said, they would ventilate her and inform us.

So, it seemed, the operation hadn't helped her breathing problems. But maybe, we thought, this problem was due to all the increased secretions as she

lay so still for the operation, or maybe it was from the trauma of the Anaesthetist's tube, or maybe we just didn't want to believe that she still had something else wrong with her that was causing all these symptoms.

We ate our meal quickly, and in silence, our earlier optimism vanished. Keith walked back to the hospital to see Zoe and I stayed to look after Oliver. I went upstairs to see how he was and he was very hot and sweaty. I took his temperature, which was 38.5C. Now what was going on? His wheeziness had increased so I gave him some more Ventolin and some Calpol and debated whether to try and find a GP and call him out. Looking back, I wrongly decided that we would ride the storm alone that night. The thought of finding an unknown doctor, dragging him out, and having to explain the whole story from the beginning was just too much - besides which I was unsure whether Oliver was bad enough to need a doctor. I decided to manage, just as we had done many a night back in Worthing, and vowed that once Zoe was over this crisis we would get Oliver properly sorted out. I say 'wrongly' as this developed into the worst attack that Oliver had ever had. His coughing increased and as he fitfully slept, his breathing became quicker and quicker. When the hospital beeped us at midnight to say that Zoe had stopped breathing yet again I was nearly at the end of my tether. She was now ventilated and quite safe, so the staff assured us that there was no need for us to go over. This was just as well because there was no way we could leave Oliver with anyone.

I lay awake all night listening to Oliver's breathing. It was very very quick. He had fallen asleep in my bed that night, so I had crawled onto the mattress on the floor between our two single beds (which was Oliver's) and lay there, just waiting for daylight.

My mind played terrible tricks on me that night. I wondered if some freak of nature was going to rob us of both our children in one night, or maybe we had been so concerned about losing Zoe but really it was Oliver that we would go home without. It really was the most awful night, every now and then calmness would intervene and I knew such thoughts were ridiculous, but then the evil thoughts of darkness would again take over.

At 5 o'clock Oliver stirred. He was quite delirious and asked me to "get rid of all the towels". I gave him some more Calpol and Ventolin and he dozed off again. As the light began seeping through the curtains Oliver's breathing finally slowed. We had nearly made it! I got up, bathed, dressed and decided to carry Oliver to the PICU as early as possible, and then if he was still breathless maybe someone there would help us. At 6.30 am I was ready, so I woke Oliver. To our astonishment he woke up, said that he felt better, and asked if he could have a bath! Yet again he had improved as soon as daylight had arrived.

After a leisurely breakfast we left Rainbow House at 8 o'clock and as we walked along Guildford Street that morning no one would have realised the terrors that the night had held for me.

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Zoe was still ventilated when we arrived on PICU and her nurse for that Thursday was a young girl called Emma who had looked after her several times. Oliver was running around by now, so it was hardly appropriate to ask one of the doctors to listen to his chest as an emergency! Instead I asked for a list of local GP's and Emma rang one and made an appointment for Oliver that afternoon. He happily went off to the Play Centre as usual. At some point in the morning Emma casually mentioned that Zoe had become wheezy. As soon as

she said this I immediately thought of little Peter who had been ventilated, become wheezy and then died. I tried to shake the thought from my mind but I just couldn't. I always knew that we could lose Zoe at any time but now I realised just how close we were. Missing a night's sleep did not help and when the tears finally started they just would not stop. Poor Emma tried to comfort me, but there was no real comfort - no-one could tell me what I wanted to hear - that Zoe would be okay, and, luckily, no-one tried. I went into the empty playroom and Keith followed, wondering what had happened. I explained about the wheeziness and little Peter. Keith had been asking me for several days to have a break from the hospital and go and stay with my friend Pip for a night. He chose that moment to say it again and got a somewhat definite and loud answer. There was absolutely no way that I was leaving my daughter, not now, not ever.

It was at least an hour before I emerged. Having coped with everything that had been thrown at us for the last 10 weeks, today I was definitely not coping. So many people had told us how brave we were and that we were coping so well and they didn't know how we were doing it - they certainly couldn't, they said. But, what do you do? If you have a sick child you just have to get on with it. No one ever imagines that they will be in the position we were in - we certainly didn't. You cannot pretend it is not happening and you have absolutely no choice but to get on with it as best you can, and hope against hope that you all come out of it together. I came out of the playroom feeling a lot better than when I went in - once again resigned to the fact that we had no control over the events in our lives and that 'what is to be, will be' (a favourite saying of my father's).

My parents had arrived shortly before my outburst, and had taken Oliver over to the hospital canteen for some lunch. Keith and I sat quietly and ate a sandwich in the Parents' Room. It was a very subdued day, with, in my mind, very little hope left now. There seemed to me to be such a fine line between life and death, and right now Zoe was dangerously close to that line. I had, several times, observed a special two-seater settee that I would see carried into many curtain-drawn cubicles on the PICU. In hushed tones the chair would be taken in, and several hours later it would be carried out again. I wondered and wondered about the significance of the chair, and then I finally realised that this settee allowed both the parents to cuddle their dying child on their laps. I wondered if we would soon be sitting on that settee.

Late the following afternoon a lady wearing a white coat came into the PICU and over to Zoe's cot. She introduced herself and said that she had been sent to take a bone marrow biopsy from Zoe. "My God!", I thought, "What are they thinking of now? Leukaemia? Lymphoma?" As I work on a ward that deals with the treatment of these conditions they immediately sprung to my mind. I asked her, and she told us that the test was to see if Zoe had a very very rare condition called Gaucher's Disease. She added that we probably shouldn't worry as she had been asked to test other children for this condition many many times, and it had always proved negative. I thought it would be just our luck for Zoe to be her first positive. I asked where she would take the biopsy from and she asked me if, due to all my questions, I was a nurse. I told her that I was, and we were then asked to wait in the Parents' Room while the procedure was carried out as she said it would not be pleasant for us to watch. We didn't mind staying, but she obviously preferred us not to.

We waited down the corridor in the Parents' Room whilst they increased Zoe's sedation and took some of the marrow from the inside of her hip bone.

We were allowed back in immediately afterwards and sat beside a sleeping, ventilated Zoe. One of the doctors, a Norwegian Senior House Officer called Thor, came over and began to chat with us. I asked him how soon we would get the results of the biopsy and he replied that they should have some idea within a couple of hours. It was soon after 4 o'clock when this conversation took place.

Pip arrived at 5 o'clock and she kindly took Oliver to the Playroom when Dr Mok came over to speak to Keith and I around 6 o'clock. Dr Mok asked us if we would be free to meet with herself and Dr Collins the next day, Saturday, at midday. She added that she should have a definite answer for us by then. After she had gone we realised the implications of what she had said and I said to Keith, "They know something already," but neither of us was prepared, at that stage, to push it any further and get the answers there and then. We needed time to think about this one.

Back at Rainbow House that night, with Pip having left, Oliver in bed, and Keith back at the hospital I spoke to Rhona on the phone. I asked her to look up 'Gaucher's Disease' in her medical textbooks. She couldn't find much information on it but managed to find one sentence which said, "Frequent causes of hypersplenism include portal hypertension, Gauchers Disease, etc. etc. Splenectomy or a reduction in splenic size by appropriate therapy relieves the anaemia and improves the neutrophil and platelet count". So maybe things were not as gloomy as all that, and perhaps removing Zoe's spleen would help her.

We slept the night, ate our breakfast and walked to the hospital as usual the next morning, constantly thinking of what we would hear at lunch time. Sitting next to the sleeping Zoe, who every now and then would wake and smile lovingly at me, my eyes were full of tears. I commented to Gail, Zoe's nurse for the day, that, knowing how hospitals' work, this meeting just had to be very bad news. She didn't deny it. I also knew that it was Dr Collins's weekend off and that she was coming into the hospital especially to see us. It was not looking good and I could not hide my despair at the last, and cruellest, blow that we were about to receive.

Keith, needing to be busy, took all our films of Princess Diana to the nearest developer to be processed. He was gone for several hours, waiting for them to be done, and Oliver was down in the Play Centre. I sat on the high stool beside Zoe's cot, watching her, and trying to get to grips with the news we were surely about to hear.

Keith returned at 11.15 am and collected Oliver. We didn't know how long the meeting with the doctors would take so we had collected him early. I had brought with me, that day, plenty of colouring books and sweets to keep Oliver entertained beside Zoe whilst we went off and spoke with the doctors, but when the time came for us to learn our fate he wanted to come too. The moment Dr Mok said that Oliver must stay behind with Zoe my nightmare became a reality. I was obviously correct in my thinking, and there was no turning back as Keith and I were silently led down the corridor to the Relatives' Room.

Once we were all seated, Dr Collins, Dr Mok, Gail, Keith and I, Dr Collins began, "I think you know what I am about to say, Mrs North, as you told the nurse this morning of your fears about it being bad news". She went on to explain that the bone marrow biopsy had shown that Zoe had Gaucher's Disease Type II. This is a rare hereditary metabolic disease due to the lack of an important enzyme called glucocerebrosidase. This enzyme deficiency results in the accumulation of a fatty substance (glucocerebroside) which is normally

produced during the recycling of cells in the body but is then broken down by the enzyme. Babies with Type II Gaucher's Disease lack the normal form of the glucocerebrosidase enzyme and are unable to break down glucocerebroside. Instead the glucocerebroside remains stored in the cells in the body preventing them from functioning normally. Enlarged cells containing undigested glucocerebroside are called Gaucher cells and these accumulate in the bone marrow, liver, spleen and brain giving rise to the classic signs and symptoms of Gaucher's Disease. Such signs and symptoms include failure to thrive, rigidity of the neck and limbs, squinting and difficulty in swallowing. Other difficulties include throat (laryngeal) spasm, seizures, and a failure to shake off colds and viruses. The spleen and liver often become enlarged with accompanying low blood counts. The lungs may also be affected. There are three types of Gaucher's Disease, Types I, II and III, and each type is different. Types I and III can be treated, but for the type that Zoe had, Type II, there was no treatment. Her life expectancy would not be greater than 12 months.

Dr Collins continued by saying that they would be happy to do anything that we felt would improve the situation. If we felt that a tracheostomy would improve her breathing problems, which it probably would, then they would be happy to ask the surgeons to perform one. But, ultimately, Zoe would still have the disease and the end result would still be the same. We all agreed that it wasn't fair to put her through yet more major surgery just to have her to ourselves for that bit longer.

Not wanting to raise our hopes too much Dr Collins did mention a type of treatment that had been performed in the United States of America in the form of enzyme replacement therapy called 'Ceredase'. She was uncertain of the results of such treatment in Type II babies so said she wanted more time to contact the doctors concerned which she would do on Monday morning.

Everything else, it seemed, was in our hands. Whilst Zoe was still ventilated she was unlikely to experience any breathing problems so she should remain quite stable. It was up to us to decide if, and when, Zoe should be taken off the ventilator, and where we would like her to be after that had happened. Dr Collins and Dr Mok both said that they would agree to whatever we wanted. The choices were that Zoe could stay on the PICU, go back to Churchill Ward, be transferred back to our local hospital, or go home. Given the dramatic events of the last few weeks I thought that Zoe would probably die quite soon after coming off the ventilator if she was not resuscitated, and both the doctors agreed with this. We, therefore, decided to stay in London and have everything happen away from home. After all, there was also the possibility that she may die in the ambulance if we transferred her elsewhere.

Keith and I both thought that there was little point in keeping Zoe ventilated now that we knew her diagnosis and poor prognosis. We decided that the ventilator should be turned off on the morning of Tuesday March 7th at 10 o'clock. This gave Keith and I the following day, Sunday, as the final day we could spend with our daughter alone, and the medical staff a final day (Monday) to perform any necessary tests on Zoe and to speak to the hospitals overseas.

Dr Mok went on to explain how Zoe came to have Gaucher's Disease. Both Keith and I, unbeknown to us, are carrying the gene responsible. Any two carriers have a 25% chance of having a baby with the disease and a 50% chance of having a future carrier. They only have a 25% chance of having a completely Gaucher free baby. Oliver, she explained, hasn't got the disease as he wouldn't have reached the age that he has, but he may well be a carrier. The neurological damage of Gaucher's Disease is irreversible and begins before

birth. Symptoms are detected from three to four months of age, just as Zoe's had been. It is a very rare condition and most doctors in general hospitals or GP's do not see a case in the whole of their working lives.

Keith and I were then left alone to digest all this information. It was all so final - there really was no hope left now - Zoe was going to die, and probably very soon. We would never again see her beaming smile, or hear her little chuckle. How would we explain it all to Oliver who loved his little sister so much? How on earth were we going to get through all this?

Keith was very keen to have Zoe Christened now. I was no longer fussed about such a thing - for me, if there was any doubt at all in my mind about whether there was a God or not I now knew for certain that there was definitely not. But, if Keith felt strongly about having Zoe Christened then I would go along with it. We later mentioned it to the staff and they said they would make the necessary arrangements.

Red-eyed we went back to Zoe. It broke my heart to look at her and know that she would soon not be with us. Oliver was in the Play Room with one of the nurses. My parents were due up the following day (Sunday) but I knew that we couldn't properly take care of Oliver and Zoe until then. I knew that my mum and dad would take Oliver to stay with them for a while so that we could concentrate on Zoe for her last few days. I tearfully rang them and asked them to come up as it was not good news. They said they were on their way.

Half an hour later Keith's mum arrived with Simon and Rachel. We took them into the Relatives' Room and told them the sad news. We all cried and hugged each other. Peg told us that no baby could have had more love. It was all so unfair - we loved Zoe so much and would continue to love and care for her whatever her condition, yet we weren't going to be allowed to.

A little while later, I don't know how long, Keith and I were beside Zoe. Simon and Rachel were with Oliver in the Play Room. There was a "Hi Ya," and Imelda's cheery face appeared around the corner. She and Ian (Keith's eldest brother) had come to surprise us. It was they who got the surprise. Keith quickly took them aside and told them the news. Then my own parents arrived with my brother. We all took over the Parents' Room and sat stunned drinking numerous cups of tea. We took turns to go and sit with Zoe, two or three at a time. I took my brother down the corridor to see her and as she looked at me with her big blue eyes she seemed to be saying, "Do something, Mum. Help me!" and it broke my heart that I couldn't do a thing. Through my tears I remember telling my brother to, "Count your blessings, Richard. You never ever know what is around the next corner". He nodded, his eyes full of tears.

Gradually the afternoon turned to evening and, group by group, the family left us to go back to their respective homes. Oliver happily and excitedly went off with my parents to stay a few nights, and play with his cousins. It made all the difference that Oliver, bless him, had willingly agreed to our suggestion. It would have been the last straw if he had been upset and not wanted to leave. We didn't discuss Zoe with him anymore in case he was reluctant to go but we did make a point of him saying a special goodbye to her.

Keith and I then sat alone with Zoe. She looked no different to how she looked yesterday or the day before, yet now everything WAS so different. Gail, Zoe's nurse, suggested that we go and get something to eat. We hadn't eaten since breakfast and didn't feel in the slightest bit hungry, but, as she reminded us, we would need our strength for the next few days and so we must eat. She recommended a little bistro up the road from the hospital and, as we no longer had Oliver's bedtime to consider, we thought a break from the hospital was a

good idea, so off we went.

We sat in the middle of the crowded, cosy, candlelit bistro amid all the romantic Saturday night couples and talked of the imminent death of our daughter and her funeral. Keith kept reminding me to keep my voice down as people began to look at us when they caught snippets of our conversation. How bizarre, I thought, when our whole world is crumbling around us the rest of the world carries on as normal.

I knew right from the start that I wanted Zoe to be in an open coffin at her funeral. We were so proud of her, and had nothing to hide, so I wanted the world to see her and be able to say goodbye. Many of our friends hadn't managed to see her in London so would never know how pretty she was with her long eyelashes, and how much she had grown. An open coffin with her 'sleeping' inside was much more natural for our baby, I felt. I had visited our local crematorium as part of a course I had attended the previous year so I did know that this option should be available to us. It was what we both wanted.

Keith suggested that Tony, our friend who works at an undertakers in Worthing, should be the person to look after Zoe when we no longer could. I immediately agreed and we decided to ring him later.

When we left the restaurant we went back to our daughter and sat with her for a while. We planned to spend the next day, Sunday, alone with her so we left fairly early that night to go back to Rainbow House and ring a few people. We have a large number of very good friends who had all constantly kept in touch with us and I desperately wanted them all to know that Zoe was soon going to die. The trouble was I had great difficulty in actually saying the word 'die'. It was all so new to us at this stage, and much as I wanted everyone to know I just couldn't ring 20 or 30 people and tell them that, finally, after all these months, Zoe was not going to make it. Each time I began I dissolved in tears upsetting the person on the other end even more. It was all very difficult. Thankfully our families helped out and rang round as many people as they could for us when they got home.

One person I did manage to talk to (just!) was Tony who promised that he would take great care of Zoe. I also spoke to our friends, Rhona and Karen, and after this I couldn't really tell anyone else - I needed to get used to the idea myself first.

It now went quiet whenever we walked into any room in Rainbow House. Conversations stopped and no-one really knew what to say to us anymore. We had met a new family the previous night whose son had had a cancer removed from his face. We had been chatting freely. Now the conversation was strained and we kept getting sympathetic looks from people. We were no longer in the same league - our child was dying and no-one knew how to react to us.

That night I spoke, once again, on the phone to Karen. She had been very upset on the phone earlier and I wanted to make sure she was okay. She asked if she could come and see Zoe the next day. Keith and I had wanted one last day alone with our daughter but this would mean that Karen might never see Zoe again or have a chance to say goodbye. I couldn't let that happen, so we agreed that Karen would arrive on PICU around 2 pm.

Our Sunday was spent sitting miserably beside Zoe's cot. I rang Clare from the Parents' Room and explained the situation. We were not interested in doing much, that day, apart from quietly thinking, and staring into space. Other parents stopped as they passed by and offered their condolences. Many cried with us. As it turned out, at 2 pm we were very pleased to see Karen and her friend Carole. They provided some light relief in what was otherwise a very very

sad day. We rang my parents a couple of times day and spoke to Oliver. He seemed happy enough and chatted easily to us over the telephone telling us what he had been doing and asking after his sister. We all agreed that if Zoe was still alive on Wednesday then Oliver would come up with my parents to see her.

Around this time I decided that it would be nice if Keith and I could spend Monday night beside Zoe on PICU. It might be her last night alive if she died soon after coming off the ventilator. We decided to ask the staff.



Monday morning arrived and Keith and I got ourselves ready to spend what was possibly our daughter's last day with her. As we washed and dressed at Rainbow House we listened to the Twinkle Twinkle Little Star tape that I had borrowed from PICU. Two of the songs were very poignant - 'Twinkle Twinkle Little Star' and 'I'm a Fluffy Little Cloud.' I packed an overnight bag for us both in case we were allowed to stay the night at the hospital.

We arrived to find a sleeping Zoe. I wanted the day to last forever, but it started to go by alarmingly fast. Lots of things were happening, each taking up valuable seconds of our dying daughter's time, but each of them necessary. Mr Pierro and his team arrived to check Zoe's progress following her surgery. He didn't know that a diagnosis had been reached over the weekend, and was quickly taken aside and told in hushed tones. He came up to Keith and I and said how very sorry he was. He had been correct all along in telling us that Zoe's problem was probably not solely reflux.

Next, Breda, one of the PICU Sisters came over and explained that soon the doctors would need to take a biopsy of Zoe's skin. This was to determine which exact enzyme was missing from Zoe, which would help with pre-natal testing in any future children Keith and I might have. We were advised not to watch as it may upset us and Zoe may be distressed. We didn't want her to feel that we had deserted her though, so, Keith stayed with her and I went to the Parents' Room. As it happened she didn't murmur when a small piece of skin was cut from her arm. Our brave daughter had been uncomplaining in just about every procedure that she had to endure throughout her short life.

Soon after this Breda explained that Zoe would soon be moved to a cubicle which would give us all some privacy. She was keen to stress that we were not being put into a side room 'out of the way' and that Zoe's care would continue to be carried out in the same impeccable manner as it had been all along (of which we were in no doubt). Breda also told us that we would not be thrown off of the PICU just because nothing further could be done for Zoe - we could stay as long as we wanted or needed to. She added that any special wishes that we had would be taken into consideration, we only had to ask.

By the time we had helped to move Zoe and all her equipment and paraphernalia into the cubicle in front of the nurses' station it was 2 o'clock. Time seemed to be galloping by and I wanted to make the clock stand still and savour these last moments with Zoe. It was odd to think that this time tomorrow Keith and I might not be there and the cot could be empty.

As we sat on the high chairs beside our daughter it slowly dawned on me that Dr Collins had been correct in her assumptions all along. It was astounding that she had known from that first conversation that we had had with her that Zoe had a progressive neurological disorder and that we would "probably not be taking her home." She was an amazing lady.

The duty vicar then called in to see us. He had been asked to come by the nursing staff following our request to have Zoe baptised. He chatted with us for a while and then, visibly moved by the circumstances, arranged to return at 5.30 pm to baptise our daughter. Zoe's nurse that day was Shelagh who was very kind and unassuming. She stayed with us while Zoe was Christened and she took several photographs.

Another subject that Keith and I had talked about at the bistro the previous Saturday night was the possibility of organ donation. Much as I couldn't bear to think of Zoe being tampered with after her death I definitely wanted to help others - to give others the chance of happiness even if we, ourselves, couldn't have it. After all, if someone had walked in the room at that moment and said that a particular organ was available that would make Zoe completely well again then all our dreams would have come true in a second. We asked the staff if any of Zoe's organs could be used after she had died. They weren't sure but they would ask the Transplant Co-ordinator and let us know. (A few hours later we were told that, unfortunately, none of Zoe's organs could be used.)

I had wanted so much for that day to last for ever, but now it was nearly over. Zoe's nurse, Shelagh, would soon be going off duty and the night shift would take over. Gail was to be Zoe's nurse for her last night on the ventilator. Keith and I had asked if we could stay with Zoe and a portable, fold-up bed had been found for us to sleep on. Nothing seemed too much trouble for the staff, and as Breda, the Sister, told us, "You only get the one chance to do everything right in these circumstances - there should be nothing that should go wrong and no regrets."

At 8 pm Shelagh verbally handed Zoe's details over to Gail before going home. She was returning the following day, giving up her day off because she wanted to look after Zoe when she came off the ventilator at 10 o'clock in the morning. We were very grateful to her, and continually amazed at the constant dedication of all the staff.

We had heard Breda spend much of that Monday morning on the telephone ringing round all the staff trying to get someone to work the night shift as one of the nurses had gone off sick. She was unsuccessful in finding anyone free to work so she had no choice but to cover both the day and night shifts herself. She left around 8 pm for a couple of hours sleep.

At around 10 o'clock that night Zoe began to cough. She coughed harder and harder, unable to stop, and her ventilator tube slipped a little way out of her nose. About 2 cms of the tube was protruding so I quickly tried to push it back in, but she coughed even harder and the whole tube suddenly slipped completely out of her nose. She was now off the ventilator. She coughed again, went blue and stopped breathing immediately. I expected everyone to stand back and do nothing. Instead Gail called for the Crash Trolley which I ran out to find. Meanwhile, a doctor dashed into the room and began resuscitation by bagging her and giving oxygen. Zoe was rigid with pinpoint pupils staring straight ahead. It was all such a shock for everyone, so sudden. We had been confident in the fact that Zoe was safe on the ventilator for one last night, but, once again, she had called the shots and decided otherwise.

While the doctor was bagging Zoe he asked us, "Mr and Mrs North, events this evening haven't quite gone to plan. I can now do whatever you wish me to. I can re-intubate and ventilate Zoe so that you have the rest of the night with her, as you planned, and then we will take her off the ventilator in the morning. Or we can just let her slip quietly away now. Take your time and think

it over. I will carry on bagging her until you decide. I will do whatever you wish." Keith and I looked at each other and we both knew that it would be selfish and unfair of us to have Zoe re-intubated and ventilated just for our own sakes, only for her to have to go through all this again the next morning at 10 o'clock. We both said that she should be allowed to slip quietly away with peace and dignity.

The young doctor removed the mask from Zoe's face. She was breathing faintly and irregularly and she looked a terrible colour. She was lying on her back, naked, apart from her nappy, and sideways in her cot. The doctor straightened her up and pulled a colourful blanket up over her. Then everyone left Keith and I alone with our daughter to say goodbye. We talked to her, stroked her head and rubbed her back. Gradually her breathing got stronger and her colour returned to normal. She was sleeping peacefully! We had her back, but for how long?

Gail returned to the room to watch over Zoe while she slept peacefully. She was now devoid of any tubes coming from her face (only her gastrostomy tube protruded from her abdomen). All the wires of the heart monitor and oxygen saturation probe had been removed so that Zoe could sleep peacefully without the constant bleeping of the machinery. Keith and I took turns to lie on the bed behind Zoe's cot, whilst one of us always sat beside her. Who-ever was resting on the bed would jump up at the slightest sound coming from Zoe, fearing that the whole process was about to be repeated.

At 2 am Zoe coughed again and her breathing ceased. Her body was rigid and blue with staring eyes. Keith and I were at her side in a second. We didn't give her any oxygen or bag her as there was little point in trying to prolong her life any longer. Instead we stroked her lifeless body and Keith whispered in her ear, "Goodbye Sweetheart. Go to Pops - he will look after you. Go and find him." She was still, and I thought to myself how little time we had had with her after all - she had only been off the ventilator for four hours and already she was gone. No more good days, or smiles.

A little sigh came from her mouth and Keith nudged me, "Look!" he said. "No", I said, "it's only the air expelling from her lungs." Gail nodded. "Goodbye darling, I love you," I whispered, kissing her forehead. Another breath, I watched her, not daring to believe what I was seeing. Then another and another. She had started up again! Our little daughter was still with us. We laughed and cried, and Zoe, yet again, slept peacefully!

From then on neither Keith, nor I, could relax. We sat up for the rest of the night, watching and waiting. Gail had decided to reconnect the heart monitor and the saturation probe on Zoe's foot. Maybe we would be able to predict another episode and be forewarned?

We didn't have to wait long. At 6 am Zoe gave a small cough and desaturated completely. She was lifeless, blue and not breathing. Keith and I were once again saying "goodbye" and I remember telling her, "Please go, Sweetheart, you can't keep doing this - you must go. Pops will look after you. Take care. We love you." She was still not breathing. "She's gone," I said, "She's REALLY gone this time." I bent to kiss her, and she took a breath. It was absolute torture - to totally believe that she was dead, and then suddenly she was alive again. Words cannot describe the utter despair and then the elation that we felt.

But this time she didn't regain normal breathing and sleep peacefully. Her breathing remained very laboured and she began whimpering as if in pain. I knew she couldn't be with us for much longer. Breda came in to help Gail, who looked totally perplexed by the whole situation. We were asked if we wanted to

cuddle Zoe, which, of course, we did. In came that dreaded two-seater settee and Keith and I nursed our daughter between us. I kept reassuring Zoe that she was doing just 'fine', and that Mummy and Daddy were with her and we wouldn't leave her alone. She looked so so poorly lying there in our arms. Everyone went out of the room again, closing the door, and leaving us alone with our dying daughter. We stroked her, talked to her, and took turns to hold her. Every now and then Gail would pop her head around the door to check we were okay.

After half an hour of listening to Zoe pitifully whimpering I could stand it no longer. She may be dying, but she should not be suffering. I asked if she could have something as she must surely be in pain. I asked about some morphine for her. "Yes," I was told, she could have some morphine, but did I realise what this could do to her breathing? Yes, I did, but I maintained that she shouldn't suffer - if the morphine took away her pain but made her breathing finally cease, then so be it. She could not go on like this - and nor could we.

One milligram of morphine was given to Zoe intramuscularly. It made her eyes, which were open, look in opposite directions. It was horrible to watch. We carried on talking to her and cuddling her but half an hour later we were still in the same predicament. The morphine, it seemed, hadn't had any effect. Dr Tasker came in the room to see us, and he suggested a sedative called Triclofos which would hopefully get Zoe off to sleep. We all agreed it was worth a try, so it was administered via the gastrostomy tube, along with a feed.

It was now 9 o'clock in the morning and both Breda and Gail, who were on night duty, should have left an hour earlier. Breda had now worked nearly 25 hours. With tears in her eyes she came and told us that she really didn't want to leave us but she had to. She doubted very much that she would see us there when she arrived for duty that night as we would probably all be gone from the hospital. Gail left soon afterwards and Shelagh took over Zoe's care for the day.

Within a short time (about half an hour) Zoe closed her eyes and went off to sleep. The Triclofos may have finally taken effect, or she was so exhausted that she naturally fell asleep, I'm not sure which. We laid her back on her cot to rest and Keith and I quickly took turns to go and wash and change in the shower-room. We had now been constantly alert for the last 28 hours.

Then we sat on high chairs either side of Zoe, in the quiet, curtain drawn cubicle. Dr Collins came and sat with us for a while. There was no need for her to speak - there was nothing more to say, she just sat holding Zoe's hand and looking at her. It was very touching that this very busy lady had taken time out of her day to be with us - she shared our sorrow and hadn't forgotten us. As she left she told us to call her if we needed her for anything at all.

Lorraine, the Play Specialist from Churchill Ward was very brave and came down to see us. The staff asked us, each time a visitor appeared for us at the nurses' station, if we would like to see them. We couldn't refuse Lorraine - it must have taken such courage for her to come down. She was a 19 year old girl and this was her first job as a Play Specialist in a hospital. The whole environment was completely alien to her. She was so nervous with us that morning that she said everything she wished she hadn't, and said nothing that she wished she had. What is more, in her panic she kept referring to Zoe as Sophie. Poor Lorraine! We all ended up laughing at the whole conversation. She told us how terrified she had been all morning just knowing that she would be coming down to see us, but she had so much wanted to come to let us know that she cared. She began to cry and hurriedly left, leaving with us a touching card signed by all the staff of Churchill Ward.

Tess (also from Churchill Ward) came to see us later that afternoon. She

said that we would be welcome back on the ward at any time. We both thanked her, but said that we felt there would be no need as Zoe would soon slip away. Her breathing had become very quick now, and we sat watching her constantly, just waiting for that breathing to stop.

But the Triclofos seemed to be working and Zoe slept and slept. Where as in the night she had stopped breathing every four hours, since she had started the Triclofos she hadn't stopped breathing at all. I figured that maybe the sedative relaxed her and her muscles enough to prevent the bronchospasm occurring. If this was the case then I wanted continuous Triclofos to be given to prevent such traumatic episodes.

Later the vicar who had Christened Zoe arrived to see how we were getting on. He sat with us a while too. Zoe slept on, oblivious to everything. We watched her - waiting for her to quietly slip away any second.

Shelagh suggested, about 6 pm, that Keith and I go to the canteen and get some supper. Neither of us could bear to go in case we missed anything, so Keith quickly went over and brought back some spaghetti bolognese for us. We didn't think we were hungry, but we managed to eat it all!

To our amazement, and delight, that night, Gail asked us if we would both like to sleep next to Zoe. She explained that she would move all the equipment out of the room, and place two mattresses in the middle of the floor. Zoe could then lie in between Keith and I on the 'bed'. We thought that this was a lovely idea and we helped Gail move everything out and make our bed up. Then we gently lifted Zoe out of her cot and laid her in the middle. I had washed her earlier and dressed her in a smart pink sleepsuit. She looked beautiful lying asleep on the white sheets. She was still attached, by the foot probe, to the oxygen saturation monitor which was constantly reading about 70%.

About 11 pm we bedded down cuddling our daughter between us. She had periods when she was awake and looking at us, intently sucking on her two favourite fingers. She looked, but she never smiled. Most of the time she slept peacefully.

We all drifted off to sleep, but each time Zoe moved her foot the oxygen saturation monitor alarmed and the Reset button high up on the computer screen would need pressing to stop the alarm. After a while we decided that this machine was more trouble than it was worth so we disconnected it. If Zoe was to slip quietly away when we were all asleep then so be it - as it was we were jumping up every 20 minutes to turn the alarm off.

As Zoe was still being fed hourly Gail watched over us all. If we were awake then we fed her, but if we were sleeping then Gail climbed over us and

fed Zoe. Feeding involved measuring the required amount of milk and pouring it down the gastrostomy tube so Zoe slept on regardless. It was all very easy provided she didn't cough and shoot the whole lot back out of the tube!

Gail told us during one of our chats that night that she was amazed to see us still there. She told us that she had never witnessed anything like the events of the previous night when Zoe died and then spontaneously returned. She told us that at one point she was watching the monitor screen (something I never thought to look at) and she had seen Zoe's heart rate drop down from 110 beats per minute (bpm) to 80 bpm to 60 bpm to 40 bpm and then finally to 20 bpm. Then, to her amazement, it slowly climbed back up to 110 bpm. She said that in all her years of nursing she had never seen anything like it before. This was reassuring to hear as I too, in my 16 years of nursing, had never experienced anything like this. It had been absolutely incredible.

When we awoke it was Wednesday 8th March. I quickly washed and changed, then rang my parents to tell them that Zoe had made it through the night. There had been a light covering of snow in Haywards Heath overnight but the main roads were clear so they would be setting off to see us soon, and bringing Oliver.

We reinstated Zoe's cot in the room and washed and changed her. She now hadn't stopped breathing for 24 hours.

As I walked past the nurses' station later that morning I overheard Breda on the telephone explaining to someone that they were full and couldn't take a particular sick child at present. I went back to Keith and told him. We both felt that now the time had come for Zoe to move from PICU. The staff had all been very keen for us not to feel pushed out, or that Zoe was a hopeless case, which we didn't feel at all. It seemed logical to us that if all the highly technical equipment which had helped our daughter for so long no longer could, then another child and it's family should have the chance that we have had. The next time that we saw Breda we asked her if we could move to Churchill Ward. She asked us if we were sure, and then set the wheels in motion for a 2 o'clock transfer.

My parents arrived with Oliver about 11 am. We all stayed with Zoe for a while then took turns to take Oliver to the Play Room. When Oliver and I were alone I quietly told him that soon Zoe was definitely going to live in the stars and that we wouldn't be able to see her again after she had gone. He asked, "When?", and I told him that no-one knew when but it would probably be quite soon. I warned him that he might see Grandma and Grandad crying, and that it was okay for him to cry too as it would be very sad. I asked him to help Grandad look after Grandma. He cried a little and said that he didn't want Zoe to live in the stars and I told him that none of us did but she was very ill and nothing that anyone could do could make her better. Subdued, he came back with me to Zoe's room and didn't stop looking at her.

That afternoon we packed up and said our goodbyes, and then helped move Zoe and all her paraphernalia through the corridors to Churchill Ward. Tess was on duty and very pleased to see us. Dad, Keith and Oliver quickly went back to Rainbow House to pack up some of our belongings ready to take home and, also, to collect some more clothes. I spent a very nerve-racking hour with mum watching Zoe and willing her not to do anything until Keith got back. Luckily she slept soundly.

The time came for my parents and Oliver to leave and they took turns to sit down and hold their granddaughter in their arms for what was possibly the last time. She looked so very ill, sucking madly on her fingers and looking up at

who-ever was holding her. I had never seen her looking so poorly. Oliver then sat in the armchair and held his sister too. She spent a long time gazing into his eyes. When she was back in her cot again and everyone was about to leave Oliver said he wanted to say goodbye one more time, so he climbed up and lay his face on the mattress next to Zoe's. He put his arm around her little body and said, "Goodnight Zoe."

That night we again bedded down with two mattresses on the floor and Zoe between us. As Tess went off duty she came to say goodbye and told us to 'take it easy with Jo', the young nurse who had often specialised Zoe on Churchill Ward. Jo had just returned from a holiday in Gran Canaria and, at that night's handover, had been in tears when she had learnt of Zoe's diagnosis and poor prognosis.



We all slept quite well that night, managing Zoe's feeds ourselves, and she awoke, still looking very poorly, to yet another day - Thursday 9th March.

I went off to the ward kitchen make Keith and myself a cup of tea. One of the other mothers asked me how "our little one was doing?". I told her that there was nothing more they could do for her, and that we were waiting for her to die. It sounded so strange hearing myself say those words. So unreal. She tearfully told me that she would be thinking of us, and hurried out.

Dr Collins came to see us again. She emphasised that we could still change our minds - if we decided to move Zoe nearer home it could all be arranged, but we were welcome to stay on Churchill as long as we wanted.

Over the last few hours Keith and I had been toying with the idea of transferring Zoe back to our local hospital. She had now been off the ventilator for three days, and she hadn't stopped breathing for two of those days, and, although poorly, she was still very much alive. Family and friends were just so far away, and now we were isolated in London for no particular reason. Nothing was being done here that couldn't be done elsewhere.

At 5 pm that evening the decision was made for us by little Zoe. Keith and I were both giving her a feed. She was sucking her fingers and looking at

us as we chatted to her and poured the milk down the tube into her stomach. Suddenly she took her fingers out of her mouth and gave us the most enormous smile, the first smile for over a week! We laughed and cried. "That's it, little girl. We are taking you HOME!" we told her.



The following day, Friday, all the arrangements were made to transport Zoe, Keith and I back to Southlands Hospital in Shoreham, Sussex. This would be a short stepping stone to home to re-acquaint ourselves with the nursing and medical staff in case we should need them in the days or weeks to come, and to accumulate all the equipment we would need to nurse Zoe.



Now that Zoe was smiling and looking slightly better we decided we would take her home and enjoy whatever time we had left with her. Our plan was to try and live as normal life as possible with her, have Oliver home with us too, and be a family once more for as long as we could. We would try and take her out in her pram to the park or beach, and not sit indoors and wait for the inevitable. As it happened this was not going to be as easy as we thought!

The weekend was spent in our little cubicle on Churchill Ward organising and planning our journey home. I made lists of things that we had to do before we left, questions we had yet to ask, equipment we would need to go home with, and whom we had to write to. I had asked my mum to buy gifts for everyone who had been so kind to us at Great Ormond Street - the PICU staff, the Churchill Ward staff, the Play Specialists, the Play Centre staff, Dr Collins and Rose. I had also asked mum to buy us a copy of the Twinkle Twinkle Little Star tape so that we could play it at Zoe's funeral.

We had now spent nearly a week watching Zoe. We had sat or slept in our clothes for six days and six nights, only leaving the room briefly to wash, change or buy food. We were already exhausted and going home was a daunting prospect, but it was what we both wanted under the circumstances - to take our daughter home for one last time.



Gail, from PICU popped in to see us on Saturday afternoon to see how we were getting on. The constant caring environment at Great Ormond Street never ceased to amaze us. 'Out of sight' certainly didn't mean 'out of mind'. The next day, Sunday, a tall, smart, elegantly dressed lady rushed into the ward looking for us. We realised it was Breda, the Sister from PICU on her day off and going with her husband to a family Christening. She just had to see Zoe one last time. She hugged us both, and then gave Zoe a lovely cuddle and a kiss goodbye before dashing on her way. I shall never forget her kindness as long as I live.

Mum and Dad came up on the Sunday and, for the first time in a week, I left Zoe's side and they and I went back to Rainbow House to empty our room. Keith found out how nerve-racking it was to be left alone with Zoe!

Suddenly it was Monday morning and the ambulance crew were waiting for us to say our goodbyes. There were lots of hugs and tears all around. Lucy, who had been off duty since Zoe's first cardiac arrest had just walked back on to the ward, and Jo and Tess were there too. Steve, the Senior Staff Nurse, was

accompanying us to Southlands in the ambulance. When all the thanking and goodbyes were complete we finally all made it to the ambulance with Keith carrying a sleeping Zoe. She was sedated with Triclofos for the journey.

For all my worrying she slept peacefully for the entire journey in Keith's arms. As the ambulance pulled in at the entrance to Southlands Hospital she woke up, on cue, and looked around.

Rainbow Ward was frantically busy when we arrived. We were allocated a temporary cot until a cubicle was available. We laid Zoe in the cot and she began to cry and wouldn't stop. All the other mothers in the bay were looking at us, probably being friendly, I'm sure, but I couldn't handle their stares and thought one was about to come over and start chatting to us. I wasn't prepared for this yet, so I quickly drew the curtains around Zoe's cot and, as Zoe began to cough, Keith and I sucked out her mouth as she couldn't swallow the secretions that she coughed up. The more Zoe cried and coughed the more uptight I became. Had we done the right thing in moving her? We knew for sure we just had to get her home as soon as it could possibly be arranged. After all those months in hospital there was no place like home.

Whilst we were waiting for our cubicle to be ready the first of our visitors arrived, my brother Richard, and his wife Hilary. They helped us move into the cubicle when it was ready. Hilary was visibly upset, and whilst Keith and I sucked out a coughing Zoe, she stood at the window with tears in her eyes. This time there were no words of comfort that I could offer. Zoe was soon to die. What can anyone say? It all seems so unfair, a little baby who hasn't even had a chance. However, my thoughts at that time were that we must not dwell on the dying aspect. Zoe was still alive at the moment and all our energies would be channelled into making her comfortable, happy and content. She was still with us and we would make the best of it. It would have seemed a terrible waste of her last few days / weeks if we had miserably sat around crying.

That evening Simon, Rachel, and Peg came to visit and brought us a Chinese take-away. Keith and I were starving as we hadn't eaten all day. It was nice to be back in familiar surroundings, and we felt very 'at home' with all the staff who kept constantly popping in to see us.

The next day, Tuesday, was spent accumulating all the equipment we would need at home. Two bin liners in the room were slowly being filled with packets of gauze, spare gastrostomy tube parts, sachets of cleaning fluids, gallipots, syringes etc.

Sister Upton popped in to see us frequently. She is a very familiar face as she has seen us through both Oliver and Zoe's post-natal periods, and I also remembered her from my training days. I could talk to her easily and we had many chats. Another very friendly face was Janet Tong's, the Manager of the Children's Ward. She is a tremendous worker, she really knuckles down and gets on with the job in hand, mucking in with the rest of them, which was an absolute pleasure to see.

My friend, Rhona, also came to see us and held Zoe for a while. Unfortunately the spiggot of Zoe's gastrostomy tube had, unbeknown to us, fallen out, so the last feed slowly seeped out all over Rhona's shirt and jeans! She didn't stay long after that!

That afternoon Kevin and Ingrid came to see us, and Dad arrived too. Oliver had developed a cough so he didn't come in but stayed in the car with Grandma. Mum and Dad had been over to our house to turn on the heating ready for our return home the next day. The only problem was, the heating system wasn't working. We decided to go ahead with the plans as we still had

an electric fire in the lounge, and Keith would fix the system once we got there.

Tony and Louise visited us that evening and we chatted easily with them. Louise remarked on how well we seemed to be coping with the situation, as had many people. As I have said before, in such circumstances you just have to carry on - there is no choice, no alternative.



On Wednesday 15th March we took our daughter home from hospital for the very last time. Keith had spent the morning driving around the area to find the part of the central heating boiler that we needed. Finally, at lunch time, he was successful and so arrived to load us all into the car. We set off for home around 3 o'clock. Keith drove and I held Zoe in my arms in the back of the car.

The journey usually took about 20 minutes, the sun was shining and it felt very strange to be part of the normal world again. Halfway home Zoe began to cry and whatever I did I just couldn't pacify her. She began to gag. Surely she was not going to die in the car on our way home? Keith stopped the car and we changed places. Zoe stopped crying once he held her, and the rest of the journey was completed uneventfully.

Being home felt very strange after all those weeks away. Zoe and I settled in the lounge with the electric fire on while Keith fixed the central heating system. Within an hour it was all working and the rooms were beginning to warm up. We telephoned Oliver at my parents house and he said he was having a lovely time. We planned to have him home at the end of the week, which gave us a couple of days to get ourselves organised with Zoe and into some sort of routine. We had boxes of food and cases of clothes still to unpack from London, all of Zoe's feeding equipment to sterilise and her feeds to be made up, and all her medication, feeding and dressing equipment to lay out in the appropriate rooms. We now had sole care of our daughter - there was no-one to call on quickly if we were worried and no-one to help deal with any crisis. We were totally alone, but very confident that we could cope.



That evening I resumed my normal position in my armchair in the lounge in front of the television. I cuddled my baby daughter, asleep in my arms, and thought how wonderful it was to be home. It felt as though we had been away for years.

We had borrowed a portable suction machine from the GP's surgery and this lay on the floor with a blanket next to it to lay Zoe on if she needed secretions sucking out of her mouth.

We crawled into our own bed that night, exhausted, but happy. Zoe was finally home, for however long, and she was sleeping soundly in her carrycot beside our bed. All we needed now was our son home to be together as a family for one last time.

Zoe's care took up every minute of every day and night. She needed watching constantly because of her potential breathing problems, quick action suction whenever she coughed, hourly gastostromy feeds, various medications regularly throughout the day, mouth care because she couldn't swallow, PLUS all the usual baby washing and nappy changing procedures. It was exhausting - we grabbed an hour's sleep in-between coughs and feeds at night, but we wouldn't have had it any other way. The energy came from somewhere and we kept going.

Oliver returned to us and he helped all that he could, pleased to be involved. He lay on the playmat next to Zoe continually making her smile and laugh. The two of them completely adored each other.

Our family and friends provided constant emotional and physical support. Many rang or visited, took Oliver out, or brought ready cooked meals around for us all to eat. It was all a great help.

I'm sure many people were worried about coming to see us. After all, what do you say to a family whose child is dying? How will they be? Many thoughts must have gone through each of their minds before they reached our house and we were very grateful to each and every one of them for coming.

Until you are actually in the position that we were, you cannot actually imagine what it could be like waiting for your child to die. And even then, I am sure, every individual is different in how they cope. Some would imagine that they would be constantly sitting around weeping at the despair of it all, but in reality this didn't happen at all. There was no time - there was so much to think about and do for Zoe, Oliver to wash, dress, feed, amuse and take to and fetch from playgroup, and a constant stream of welcome callers. Besides which, Zoe was still alive, and all the while that the blood was pumping around her little body I was happy. She was still our beautiful little girl and was looking to her mum, dad, and brother for comfort and total care. This she would get from us, day and night, until the very end.

Fleetingly, several times during that first week at home I wondered if the doctors could possibly have got it all wrong. Perhaps a mistake had been made and Zoe had some simpler condition that could easily be treated. But, in my heart of hearts I knew that we were on borrowed time and we were just lucky that she seemed so well.

Zoe loved to lie on her playmat on the floor in front of the television, sucking her two fingers and watching the moving colours on the screen. She would roll over, from side to side, and was, I believe, happy and in no pain. At night we sedated her with Triclofos which enabled us all to get the maximum sleep possible (although this was usually not more than 2 - 3 hours, often less!). However, it was always worth it just to see Zoe's smiling face the next day. She loved to be held sitting up on our knees so that she could see our faces. We would chatter to her and she would flutter her long eyelashes and her whole face would light up with a lovely smile. She also loved to listen to a Rock ' n ' Roll tape that we had. We would play it loud and Keith would dance around the room, with an upright Zoe held to his chest. She would laugh out loud and love every minute!

We took many photos at home, knowing that time was running out, and we tried to capture every precious moment on film. Many of the photos were of Oliver with his baby sister, lying together on the playmat, or cuddling up in bed. He wanted to be with her every minute that he was at home and would love to make her smile. "Look Mummy, isn't she pretty?", he would say over and over again, and "Aaah, that's a lovely smile." "We do love her, don't we Mummy?".

We had been at home for one week when Zoe stopped breathing for the first time. I was downstairs, about 9 o'clock in the morning, changing her nappy and washing her on the changing mat on the lounge floor when she gave a little cough and suddenly became completely lifeless without warning. Her little head rolled over to the side, and she was blue. Oliver had been beside me, helping, so I told him to quickly go and get Daddy. I shook Zoe gently, hoping for a response. There was none. Oliver returned saying that he couldn't find Daddy, so I screamed loudly for Keith and Oliver disappeared. Keith came and we tried to suction Zoe's airway, thinking that some mucus might be blocking it. After a while she took a breath, then another, and another. Her colour returned to normal - she was back, and she gave us a big smile to prove it!

Seconds later the phone rang. It was my friend Elaine but I couldn't speak much so I said I'd ring her later. I then found Oliver sitting on the stairs crying - frightened by my shouting and the events of the last 20 minutes. The poor boy was distraught, having heard the panic in my voice, and I vowed that whatever happened in the future we must always remain calm and involve Oliver so that he was helping. From that moment on he always stayed with us when there was a crisis, he would pass the suction tubing to us, turn on the suction machine, or get whichever parent was missing from the room whenever there was a problem.

The weather that year, in March, was sunny and fairly warm. We took Zoe out in the garden for some fresh air in the afternoons. She lay, wrapped in blankets, in her pram, the portable suction machine on the rack under the carrycot. One afternoon I dared to venture to the shops up the top of our road with Zoe in the pram, the suction machine underneath, and Oliver running along beside us. I had a long shopping list but gave up after the first item when Zoe began coughing. I quickly took off her blankets to see if she was changing colour, and the shop-keeper remarked, "Nasty cough, that. Terrible! Ought to get that seen to!". The thought of Zoe dying in that shop was more than I could bear, so I hurriedly left and ran home pushing the pram as fast as I could, with Oliver worried that we'd forgotten to do all the shopping. Zoe never left the house again.

After the first week Keith and I slept with Zoe in between us in our bed. We felt that it was more comforting for her to be near us, and it was easier for us to hear her breathing and detect any problems early. Any little sound from her would have us wide awake and ready with the suction machine on. She was developing a chest infection, which we knew would not be treated, and she was coughing up thick yellow/green sputum which she couldn't swallow. We were constantly alert all night. Oliver, feeling lonely on his own in his bedroom, had asked us a few nights previously if he could also sleep with us in our room. We didn't want him to feel left out, so we made him up a bed on the floor beside us. With five bedrooms we were now all crammed into one!

One morning, in the early hours, following suctioning Zoe and feeding her down the tube, we just couldn't get her to settle so I was pacing around the bedroom with her in my arms. I was surprised to see Oliver awake, in his made-up bed on the floor, and watching me. "Hello, Sweetheart. What are you doing awake?" I asked him. "Ummm, I'm picking daffodils," he cheekily replied!

APRIL

On 1st April we had been home for 17 days. Zoe's condition was deteriorating rapidly and her episodes of stopping breathing were becoming more and more frequent. I wondered how much more her little heart could take. She had stopped breathing as soon as she had woken up that Saturday morning, and then did so another three times in the next two hours.

Keith dropped Oliver off at his mother's house and we cancelled all our visitors. We both lay on the floor with Zoe watching her poor little tormented body endure all this torture. We would say goodbye to her lifeless form time and time again, hold her hands, kiss her, then slowly the breaths would start up again. Much as her body wanted to go, her mind fought all the way to stay with us, and she came back from the brink time and time again.

It was the most draining emotional experience that I have ever experienced. To cry with utter despair and sadness looking at your daughter's blue, lifeless body, only to see her pink and breathing and smiling again five minutes later. The confusion, elation, relief, and above all, overwhelming sadness, because in your heart you know that the happiness is only temporary and very soon she will be gone for good.

For the rest of that day Zoe slept, sedated with Triclofos.



Occasionally, during our time at home, Zoe would become distressed and cry and cry inconsolably, as if she were in pain. Usually, walking around with her in our arms would settle her, and we would take turns to walk miles with her around the house. Very occasionally this would not work and she would give a continuous pained cry, which was very distressing to hear. I was adamant that Zoe should never have to suffer, and that she should not have to be upset during the short time that she had left to live. To be caring for a dying child is bad enough, but an inconsolably crying dying child is too much for anyone to bear. It is unfair on the child, and those that have to watch. I maintained that if sleep eased her suffering then she must be sedated more - but only if there was

no other way of consoling her. For this purpose our GP prescribed some Vallergran to give her in addition to the Triclofos. Luckily we only had to use this combination about four times during Zoe's time at home.

Zoe's chest infection was now taking hold and she was very sleepy. She had also begun to have mild fits where she would arch her back and jerk rhythmically for a few seconds. Her overall condition was deteriorating fast, and we knew that we couldn't have much longer left with her. Every evening we would kiss her goodnight and never know if we would see her in the morning. She was too poorly to smile now, and she would just look sadly at us.

We wanted time alone so we could concentrate on Zoe for her last few days so we asked various friends who had arranged to visit us not to. As Breda, the Sister from Great Ormond Street, had said, "You only have one chance at this, and you must get it right the first time." We channelled our final efforts into caring for our dying baby.



On Wednesday 5th April Zoe seemed a little brighter. She was more alert, and didn't cough quite as much. As she was slightly better we agreed that our friends, Tony and Louise could visit that evening. They came for about an hour, during which time Zoe gave one of her beaming smiles, the first for several days. We thought she was over the worst of this crisis.

The next morning, Thursday 6th April, Zoe woke, as usual, around 7 o'clock. I carried her downstairs and began the usual two hourly ritual of washing and changing her, swabbing out her mouth, cleaning her eyes and dressing her gastrostomy site. She smiled and watched the television as I did so. By 11 o'clock she was sleeping soundly on the playmat on the lounge floor.

My parents were due down that morning, but Dad arrived alone - Mum had a bad throat infection and was staying in bed. Dad and I were sitting chatting in the lounge while Keith went to collect Oliver from playgroup. As I heard Keith drive up the road Zoe gave a little cough and stopped breathing. It was a horrible feeling - Keith and I had always been together whenever she had stopped breathing before, and now, if she didn't pull through this one, Keith would not be with her when she died. I picked Zoe up - no response, and still no breaths. She was blue with her tongue protruding from her mouth. I tried to suction her but it was no use - she still didn't take a breath. A minute, maybe more, went by. "She's gone Dad," I said. He held her little hand and said goodbye. Then he said, "Look!" as Zoe took a breath, and then another. She struggled on until Keith finally arrived back, but it wasn't long before she stopped again, and again.

Keith and I stayed on the floor with Zoe for about an hour, while Dad read stories to Oliver on the settee. When Zoe stopped breathing for the fourth time Keith and I waited several minutes until we were sure she was gone before we called Oliver over to tell him. As Oliver walked across the room Zoe started breathing again. It was like a nightmare that could not possibly be true, and had I not witnessed it - I would never have believed it. My dad was the only other person, apart from Keith, myself and the medical staff, to see Zoe having one of these episodes.

Finally Zoe fell into an exhausted sleep and we lay her on blankets on the floor. Keith and I lay either side of her, listening to her laboured breathing. We decided it would be a good idea for Oliver to go back home with my dad so that we could concentrate all our attention on Zoe. I packed an overnight bag for

Oliver and he said a special goodbye to his sister before happily going off with Grandad.

Keith and I spent the rest of the afternoon and evening beside a sedated Zoe. By late evening her breathing had returned to normal and she slept peacefully. At 9.30 I rang my Dad to see how Oliver was. He had had a good tea, a bath, and was fast asleep in bed. I told Dad that Zoe was sleeping soundly and had had no further episodes.

However, at 10 o'clock she did stop breathing for a short time but returned to us fairly quickly. The episode woke her up, so I took the opportunity to wash and change her. I washed her pale, exhausted, limp body all over, and Keith dried her. I changed her nappy, and put on the last one that we had. I made a mental note to remember to buy some more first thing in the morning. I dressed her in a pale yellow sleepsuit and settled her down on the playmat for the night. We had all taken to sleeping downstairs on the lounge floor in sleeping bags for the last few nights as it seemed that the change of air up in our bedroom made Zoe cough even more.

Zoe was sleeping peacefully. At 11.15 pm she gave a small cough and, as we watched, the life slowly ebbed from her body, and it didn't return. She had lost her brave fight to stay with us and had quietly slipped away as we held both her hands.

With a shocked numbness we took turns to cradle her in our arms. We talked to her, telling her of how we would miss her, and wondering out loud what her brother would do now without her. We told her how brave she had been, and how proud we were of her. We sat for hours cuddling her and talking to her. I held her upright, against my chest, with her little head resting on my left shoulder, something I had been unable to do when she was alive as her neck would not allow her head forward.

Unbelievably, it was a beautiful although incredibly sad night. Given that we couldn't change the final outcome, all of the contributing factors were as we would have chosen them. Zoe died at home, with both Keith and I at her side. There was no-one else around, and, being late at night, no phone ringing or callers at the door. We then had a final night alone with our daughter before we had to face the world. We knew we had 'done it right and with no regrets.'



That night I lay in bed with Zoe's body next to mine. She lay on her side, facing me, and I held both her hands. There was no noise anywhere - no sound of her breathing or coughing, no suction machine, no Oliver breathing heavily in his sleep. Just silence and stillness. Absolute silence.

The memories of that night are very special to me - it was the last I would ever spend with my beloved daughter. I dozed in and out of sleep, and each time I awoke I was looking at Zoe's pale, but peaceful, face. The night gave me time to gather my thoughts and take in the fact that she had really gone. It was strange knowing that nobody else knew.

Early the next morning we began the dreadful task of ringing family and friends before they left for work. It was very difficult to actually say the words, but it had to be done time and time again.

I rang my dad and told him, then asked to speak to Oliver. Oliver told me he was having a lovely time. He had just had breakfast, and was watching a video. Then he said, "How's Zoe, Mum?" "Zoe's in the stars now, Sweetheart" I told him. "Do you mean she's died, Mum?" "Yes, she has, Darling, her spirit is

up in the stars, but her body is still here. Do you want to come and see her?". "I'm coming, Mum." he said.

Our family began converging on the house. Keith's mum, Simon, Rachel and Kevin, being the nearest, came first. I had placed Zoe back in her carrycot and tucked her in with blankets. It looked as though she was sleeping peacefully. The carrycot rested on a chair in front of the patio door, and I sat next to the cot rubbing Zoe's back, as I had done for the past five months.

That morning I drank tea, ate toast, spoke on the phone, answered the door, and, somehow functioned, although I felt far from normal. It all felt so unreal to be sitting talking while our dead baby was lying in her carrycot beside us. I couldn't work out what else it was that we should be doing, so we all carried on. It felt bizarre that I was so calm after such a major catastrophe, but I suppose we were numb. The real pain was to come in the weeks, months, and even years to follow.

My parents arrived with my brother and Oliver. Oliver was excited to see all his aunts and uncles together, and he ran outside and started playing in his sandpit. I was very keen that he should see Zoe and realise that she wasn't breathing anymore and it was only the empty shell that was left, but, at first, he was reluctant. Maybe he was frightened of what he would see, I don't know, but eventually in his own time he came in and leant over the side of the carrycot and kissed his sister for the very last time. He commented on how 'wet' she felt as he wiped his mouth with his sleeve. She was, by now, icy cold and, therefore, felt wet to him. He ran back outside and played football with his grandad and uncles. The questions came later.

I was told it was lunch time, although I felt no hunger, and the Mums busied themselves in the kitchen warming soup for everyone to eat. We all sat around the dining room table and had some lunch. Keith and I found it very strange to sit and eat a meal without walking around with, or holding, Zoe. It felt as if part of us was missing.

The vicar came to say how sorry he was, as did our GP. They didn't have to say much, there wasn't much to say, just the fact that they came was enough. Then, after lunch, Tony and his colleague came to collect Zoe. We sat quietly and discussed the funeral, and then came the saddest part of all - taking our daughter, in her carrycot, out to the waiting car, handing her over, and watching her be driven down the road, away from us forever. I felt desolate, frantically waving, tears streaming down my face, until I could no longer see the car in the distance.

That evening, after everyone else had gone home and it was dark, Keith and I took Oliver outside into the garden. We let him choose Zoe's star. He chose the biggest and the brightest star in the whole sky, blew her a kiss, and said, "Goodnight Zoe".



The following morning there was nothing for me to carry downstairs, and nothing to do when I got there. All I felt was emptiness and a lack of purpose. Zoe's care had taken up 24 hours of every single day for several months, and now, suddenly, we had absolutely nothing to do. The house seemed very very quiet, still and very very empty.

The cards, letters and flowers then began arriving in earnest. Bunches, bouquets and baskets of flowers were being delivered from family and friends near and far. All contained simple messages about our beautiful little girl. She

seemed to have touched so many peoples' lives during her short stay with us. We received over a hundred cards and letters from people, many of whom were close to us, and some we hardly knew. It was very touching that so many people were thinking of us at this very sad time.

One friend, Claire, sent us a lovely poem. The words I find very moving, even though I no longer have any belief in any sort of God. The poem reads :-

GOD'S LENT CHILD

I'll lend for you a little while, a child of mine, God said,
for you to love while she lives, and mourn for when she's dead.
It may be six or seven years, or forty two or three,
but will you, till I call her back, take care of her for me?
She'll bring her charms to gladden you, and should her stay be brief,
you'll always have her memories as a solace in your grief.
I cannot promise she will stay, since all from earth return,
but there are lessons taught below I want this child to learn.
I've looked the whole world over in my search for teachers true,
and from the folk that crowd life's lane I have chosen you.
Now will you give her all your love and not think the labour vain,
nor hate me when I come to take this lent child back again?
I fancy that I heard them say Dear God, thy will be done.
For all the joys this child will bring the risk of grief we'll run.
We will shelter her with tenderness, we'll love her while we may,
and for all the happiness we've ever known we'll ever grateful stay.
But should the angels call her, much sooner than we'd planned,
we will brave the bitter grief that comes and try to understand.



We spent the next few days organising everything that is necessary following a death, and trying to keep ourselves busy. In reality there was a tremendous amount to do, but it felt like there was just nothing to do anymore. The house seemed so empty, and even with a lot of noise going on - it still seemed quiet. A huge part of our lives was now missing and we had a lot of adjusting to do. Keith threw himself into re-arranging the garden. He began to dig an allotment for Oliver so he could begin growing vegetables. I busied myself in the house, and continually answered the telephone and doorbell.

We also had the funeral to think about. The date was set for Thursday 13th April at 11.20 am. We wanted a simple service at the crematorium, and we asked our local vicar, who had visited as a friend since Zoe had been ill, to conduct the service. We didn't want any hymns (only nursery rhymes) or anything too religious - just a beautiful farewell for our beautiful child.

Unexpectedly for me, our request to have Zoe visible at the funeral apparently caused quite a stir at the undertakers. This had never been requested before, and therefore they had to make various enquiries before it could be agreed upon. In no time at all it was all sorted, and yes, we could have Zoe in an open coffin but certain rules of the land must also be adhered to before, during and after the service. These included having the body covered for the journey in the hearse to the crematorium (obviously so as not to upset onlookers in the streets) and the outside doors of the crematorium, once we were inside, be shut, while Zoe's face was uncovered.

In a funny sort of way I was looking forward to the funeral. It gave us something to plan for, and it helped a little to fill the void that Zoe's death had left us in. It would be the last thing that we would ever do for our daughter. I wanted it to be absolutely perfect. And it was.

One thing I didn't want was for people to feel that they HAD to attend. I only wanted those family and friends to go who felt that they could. If it was to be a huge ordeal for them then I would rather they said and didn't go. Anyone could say their own farewell to Zoe where ever they were, they didn't have to go to the funeral to do so. Having said that, we were delighted to find the crematorium packed with people that day, and about 70 - 80 people attended. We decided, after lengthy discussions, that Oliver should not go. We felt that he was too young, and that it would greatly distress him to see everyone he knew so upset. He had said his special goodbye to Zoe at home several days earlier, so on the morning of the funeral he went to the park with my mother.

As Oliver was not attending the funeral we felt it would be unfair if his cousins or any other children went. He would have been extremely upset if he had found out in later years that other children had been there and he had not, so Keith and I asked that no other children be present.

We also asked that, if people did not want to send flowers, but wished to make a donation this would be to the Childrens' Ward of our local hospital, Southlands. Zoe was born there, and was cared for there when she first became ill. We hoped that some other children could benefit from any money received. Several hundred pounds was donated.

For our part, Keith, Oliver and I had a spray of flowers made for Zoe in the shape of a large white star. I asked Oliver what he would like to say to his sister. He said, "To my Zo Zo. Goodnight little star. Love Oliver." This is what we wrote on his card.



It was a beautiful sunny day when Keith and I walked up the slope to the chapel on the morning of Zoe's funeral. Inside the packed chapel, with the doors closed, we uncovered our daughter. She looked peaceful and serene. She was dressed in the North family Christening robe, and lay on her side with her hands clasped together by her mouth. We each took a handle of her Moses basket and carried her, very proudly, inside. Music played...

Twinkle Twinkle Little Star
How I wonder what you are
Up above the world so high
Like a diamond in the sky
Twinkle Twinkle Little Star
How I wonder what you are
Twinkle Twinkle Little Star Twinkle Twinkle Little Star
How I wonder what you are.

When the blazing sun has gone
When he nothing shines upon
Then you show your little light
Twinkle twinkle all the night
Twinkle Twinkle Little Star
How I wonder what you are.

Then the traveller in the dark
Thanks you for your tiny spark
He could not see which way to go
If you did not twinkle so
Twinkle Twinkle Little Star
How I wonder what you are.

In the dark blue sky you keep
And often through my curtains peep
For you never shut your eye
'Til the sun is in the sky
Twinkle Twinkle Little Star
How I wonder what you are.

As your bright and tiny spark
Lights the traveller in the dark
Though I know not what you are
Twinkle Twinkle Little Star
Twinkle Twinkle Little Star
How I wonder what you are.

We placed the Moses basket at the front of the chapel and took our places. The vicar, Father Keith Woods, spoke to everyone on our behalf...

"At our baptism, we're often presented with a lighted candle, and bidden to "shine out" as a light in the world all our days.

Zoe's baptism candle, here, "shines out" as a little light of hope and joy for us today, even in the darkest of our grief and sorrow: for in her short life, Zoe has touched and blessed the hearts of so many, a bright light that will never be extinguished. She was such a beautiful baby, with that most lovely and infectious smile, and those ever so long eyelashes: and who'll forget her special characteristic, insisting on putting anything from two to five fingers in her mouth: no mere "thumb sucker" was Zoe!

She has brought hope and joy to so many of us and, not least of all her big brother, Oliver.

You may have seen that lovely photo of Oliver kneeling down beside Zoe, their faces truly a picture, lit up with affection for one another. He simply doted on his little sister, to the extent, that anything he made or created at playgroup was always for Zoe; I'm afraid Mum and Dad never got a look in!

And although, of course, much time and attention had to be devoted to Zoe, there was never a hint of jealousy in Oliver.

And not only was Zoe a very beautiful and loveable baby, she was such a courageous and brave soul too: she really fought terribly hard against her awful and debilitating illness.

Keith and Cath waited a long time for Zoe to come along, she was so much wanted, and very special to them, and nothing can take away the heartbreaking pain they, and we all feel; but, yes, we can still give thanks today, for Zoe truly was a light of hope and joy, and we shall never forget her.

Keith and Cath have also asked me to thank on their behalf, their family and many friends, their chums and work colleagues, for all their very considerable help, support and concern; for all the visits made to where ever they've been with Zoe; for the letters and phone-calls; for meals provided; and for help in looking after Oliver.

And, of course, they're so grateful to the nurses and other staff at the hospitals they've been with Zoe; the Rainbow Ward at Southlands; the Nicholson Ward at the Royal Alexandra in Brighton; the Intensive Care and Churchill wards at Great Ormond Street; all the staff have been unstinting in their care, concern and love.

They would also specially thank today Tony Offer, a good friend who works for Dillistone, and who has continued to take care of Zoe when they no longer could.

In her adversity and helplessness, little Zoe was truly a light of hope and joy, engendering so much good will, compassion and love; so let us now commend her trustingly to our loving Lord, giving thanks that she's been brought, through her death, to that Eternal Light that is the full glory of Almighty God, in that place where there's no more pain nor crying, and where, one day, we shall be reunited with Zoe, and all our loved ones who've gone before us, together in our true home in Heaven."

Another song played....

I'm a fluffy little cloud
Floating in the sky
Cheering up the raindrops so they won't cry
Frightening the lightening
Chasing off the rain
Making sure the sun comes out again.

I'm a fluffy little cloud
Floating on the breeze
Warming up the snowflakes so they won't freeze
Frightening the lightening
Frowning at the frost
Making sure the sunbeams don't get lost.

I'm counting all the colours in the rainbow
Checking that the sun's got a smile
Making sure the clouds full of rain go, so
We all live in style, for once in a while
Don't you wish that you could be a fluffy little cloud like me?

Keith and I went up and said our final goodbye to Zoe and then we led everyone outside. Those who wished to went up and paid their last respects to our very own little Star.....



PART TWO

OLIVER

Oliver was three and a half years old when Zoe died. He is an amazing child who has developed an understanding far beyond his years. Throughout his sister's illness he was never jealous of all the attention that she, quite rightly, received. He, along with the rest of us, absolutely adored her, and would do or give anything to help her.

Our simple explanation to him that Zoe's spirit, after she had died, was in the stars was quietly accepted by him, and the most frequent question since her death has been, "WHY did Zoe die?". We always explain that she was born with an illness, and for her particular illness there was no treatment. Her little body was too ill to carry on living, and so she had to die.

Around the time that we returned from Great Ormond Street Hospital and were nursing Zoe at home, I contacted our local hospice, St Barnabas. I asked them if they knew of any books that would help me explain Zoe's imminent death to Oliver. My conversation with Lucy in London about this subject had drawn a blank. No-one seemed to know of any such books. Luckily, although St Barnabas deals only with adults, the Social Worker, Julia, could recommend two books to me. Both were aimed at children whose dying parents were being cared for at the hospice, but they covered the subject of death in general terms. She loaned them both to us. One book described how all living things (plants, animals, and people) have beginnings and endings, and the time in-between is a 'life time'. Some lifetimes are long and some are short. Sometimes people are too ill, or too old, to stay alive any longer and so they die. Oliver found both these books helpful.

The hospice also gave Oliver a scrapbook to complete. This allowed him to write about his sister and add his drawings and photographs. He had to describe his family, the house where he lives, the person in his family who is ill, the part of them that is ill, and why they are different from people who are well. Oliver and I took time to complete this together during the weeks preceding Zoe's death.

Some other frequent questions from Oliver have included, "Does she still need suction when she coughs up in the stars?", "Who is putting the milk down her tube now?" and, "Has she still got a tummy button?". Countless times we tried to explain that it was only her spirit that was in the stars, and not her actual body, but this then provoked further questions about what had happened to her body. We didn't want to go into the details of the cremation so we simply said that her body, now an empty shell, had been turned to ashes. Several weeks later we were speechless when Oliver, completely out of the blue, asked where the 'flashes' had gone. He had misheard us!



Conflicting stories confused Oliver. We had explained to him at great length that it was Zoe's spirit, the part of her that felt love and happiness, that was up in the stars. We emphasised that her body was not floating around in the sky and assured him that she didn't have a tummy button, feeding tube or face anymore. We were consistent in our explanations and Oliver did not question them. However, he was slightly perturbed when he heard someone saying that they could 'picture Zoe sitting on Jesus's lap'. "But she can't be," he interrupted, "she hasn't got any legs!"

Another time when we were lost for words occurred soon after Zoe's death. We deliberately kept Oliver playing in the garden when Tony came to

take her body away so that he would not witness the event. We did not want him to continually associate Zoe with Tony and maybe be upset whenever he saw him in the future. However, a few days later Tony returned with the empty carrycot, and, on hearing the doorbell, Oliver came to the door to greet him, seeing the empty carrycot. Hence came the question that evening, "Mum, how can Uncle Tony go up into the stars and come back, but we can't?". I explained that Tony's work involved caring for peoples' bodies after they had died, and that he had looked after Zoe's body for us. Her spirit, though, had long since gone.



Oliver is a sensible intelligent boy who works everything out in his mind. He is very inquisitive, with a very active imagination and an incredible memory, often remembering events from years gone by which we had long since forgotten. We tried to prepare him, as much as we could, for Zoe's death before it actually occurred, but it was very difficult for him to grasp something that he had never encountered. It is also very hard to explain what is, essentially, the unknown. Afterwards, in many ways, he grieved as an adult. He certainly displayed the denial stage of grief. This manifested itself on two separate occasions. The first was several weeks after Zoe had died. Oliver and I were shopping in our local Woolworths and surveying the toy section. He pointed out a colourful baby toy, picked it off the shelf and said, "Hey Mum, let's get this for Zoe". He was very very insistent, and I could not believe my ears. Had he really not understood after all that we had been through? We didn't actually buy the toy, and Oliver left the store reluctantly. Despite my arguments, he was still not completely convinced that Zoe wouldn't need it.

The second time was several weeks after Zoe had died. My parents were leaving our house after visiting us for the afternoon. They took with them the baby car seat which we had borrowed from my brother and his wife. As my dad lowered the seat into the boot of his car Oliver declared, angrily, "Don't take that Grandad. That's my Zoe's. Leave it here". It was very hard, at times, dealing with his grief as well as our own.

Sometimes Oliver reverted back to babyhood. He would climb onto my lap and ask to be held like a baby. He would say "Aghoo" and smile, just as Zoe had done, and then climb off and carry on playing normally. Having read many books on the subject of child grief I now know that this mild behaviour pattern was perfectly normal.



Zoe had accumulated many cuddly toys during her short life, and one afternoon, after she had died, I laid them all out on a bed and asked Oliver if he would like to choose one and look after it for Zoe. He chose a grey teddy bear, which was given to Zoe by her Uncle Ian and Auntie Imelda. I asked him what he would like to call this teddy, and he replied 'Zoe' which became quite a conversation stopper over the next few months! This Zoe accompanied Oliver on many journeys and slept beside him every night.

Oliver also asked if he could have one of our many framed photographs of his sister to keep in his bedroom. He chose my favourite picture of her, sitting up smiling five days before she died, and placed it beside his bed. Unprompted, every night he would get into bed, kiss the photograph and say "Goodnight Zo

Zo” before replacing it back on his bedside table. Invariably, at some stage during the evening, I would go upstairs to check on him and find him fast asleep, yet again clutching the photo!



We were always very honest with Oliver about Zoe’s illness. Some would probably say too honest, but we believed honesty was the best policy. He was never told anything that was impossible for him to deal with, and everything was simplified so that he could understand. His sister’s death has had a profound impact on his life, but, we feel, it has not been detrimental to him.

During such times of emotional crisis there is no-one to tell you whether you are doing things right or wrong - there are no rules to guide you - you just have to make them up as you go along and hope that you are doing the right thing. There is, also, hardly any time to prepare, suddenly you are thrown into a situation that you just have to get on with. The only certain thing is that there is no going back and you really must get it right the first time.

We involved Oliver from the first day of Zoe’s life until the last. We never pretended to him, lied to him, or shut him out. We always talked about Zoe freely, both before and after her death. In return he rewarded us with compassion and sensitivity. It was difficult to believe that he was only three and a half years old. In the weeks and months following Zoe’s death Oliver was a huge comfort. If he found Keith or I upset he would immediately know why and put his arms around us. “We did love her didn’t we?” was his favourite saying at such times. During these conversations he wouldn’t usually cry, but some nights when he was in bed waiting for sleep I would hear him crying. When I went to him he would say, “I just want my Zoe back”. I would climb into his bed and we would talk about Zoe until he fell asleep.

Around this time Oliver was learning to write. One of the first words he learnt to spell was his name, which was always accompanied by Zoe’s name. At every opportunity he would write Oliver and Zoe, whether it be on paper, on a blackboard, in sand, or at the dinner table with his alphabet shaped chips. His early drawings of pinmen people also always included his sister.



Certainly the frequency and severity of Oliver’s asthma attacks increased around the time of Zoe’s illness and death. This was probably coincidental but nevertheless the nature of the symptoms gave Oliver cause to fear for his own life. At times he became very frightened. Some night-times he would cough and cough, and as coughing was a dominant feature of Zoe’s illness Oliver was obviously concerned, despite many reassurances. “I will get better, won’t I?” and “I won’t die, will I?” became frequent questions. We explained to him that his cough was completely different to Zoe’s and it occurred for different reasons. However, we could see that he didn’t really believe us - especially when, during a particularly bad attack of wheeziness our GP gave him a nebulizer, which he had seen Zoe have many times.

One Saturday, when Oliver had been pale and unwell with a high temperature for several days, we made an appointment and took him along to the local doctor’s surgery. On the way I sat in the back of the car with him while Keith drove. Suddenly, out of the blue, Oliver asked what time Zoe had died. I told him 11.15 pm. “So what time will I die Mummy?” he asked.

Zoe had a huge impact on Oliver's early years. He would spontaneously include her name in conversations, draw pictures of her and worry about her well-being. He was most upset on his fourth birthday (six months after Zoe had died) when her name was not included with ours on his birthday card, or at Christmas time when cards arrived for us but did not mention her name.

In the summer, a few months after Zoe had died, we watched a loud firework display late one night on the beach. Oliver loved the fireworks but suddenly, without warning, began to cry. He had seen Zoe's star above a loud rocket that had just exploded and he thought that she would be very frightened by all the noise. We assured him that Zoe was okay and was probably enjoying the fireworks just as much as he was. He gave her a big wave, blew her a kiss and enjoyed the rest of the display.

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The song Twinkle Twinkle Little Star obviously has a special meaning in our household now. It is played loudly, and sung along to, on special or sad days. I know that Oliver sang it loudly and proudly at his playgroup, and, he told me, he often spoke of Zoe to his leaders and friends. He has just recently started school and he cried the first time he tried on his new school uniform as he said his sister would never see him looking so smart ready for 'big school'. Late that night Oliver, Keith and I stood in the garden, in the dark, with a smiling Oliver proudly showing Zoe's star just how smart he was!

✪✪

Whenever Oliver is awake late enough to see the night sky, where ever we are, he will always pick out Zoe's star and say a special goodnight to his beautiful little sister. "I was a good brother wasn't I, Mummy?" he asks, and I always reply, "Yes, Sweetheart, you were the best brother in the whole wide world....."

✪✪

US

It is nearly two years since Zoe's death. We speak of her often, and, of course, we miss her terribly. The pain will never leave us. Our only comfort is knowing that we did absolutely everything possible for her when she was here. We were always there when she needed us and we rarely left her side. I know that she could not have had more love from anyone. I will be eternally grateful that I was granted time off work to be with her for the short time that she was ours.

Our family and friends wrote some beautiful words to us after she died, in letters, cards, and on the flower arrangements at her funeral. Some special reminders of her we now keep in a pretty box which is 'Zoe's box.' It contains many of her precious belongings including one of her favourite toys, the hospital wristband she wore after her birth, the sleepsuit that she wore on the last day of her life, all the bravery certificates from the various hospitals she stayed in, and all the letters, cards and poems we have received for her.

Once Zoe died the focus of our lives suddenly changed. There was no longer this tiny human being who needed our constant care and attention. The desolation and acute sense of loss was completely overpowering. We functioned on a practical level and assured people that we were fine, and that 'we couldn't have wished for her to go on any longer' but, in our heart of hearts, of course, we had desperately wanted her to stay with us forever.

In the last two years we have had many hurdles to negotiate - some have been easy, some extremely hard. The whole experience has certainly changed us both, without a doubt.



Anniversaries and special days have been very difficult, although the build up to the day is often worse than the actual day itself. The day that should have been Zoe's first birthday we opened all the letters and cards, had some tears, then packed a picnic and went out for the day. We needed to be alone together and doing 'something'. Everything considered we had a fairly nice day. We gave Oliver a present to mark the occasion. We explained to him that as Zoe couldn't have a present we were sure that she would want him to have one, and the marble run that we gave him has provided him with hours of enjoyment. We will continue to give Oliver a present every year on Zoe's birthday.



Keith and I scattered Zoe's ashes one rainy Thursday morning in June in the tranquil gardens of the Crematorium. Our friend, Tony, came with us. We carried the casket containing our daughter's ashes. At the prepared site we lowered the casket to the ground and Tony helped us gently lay Zoe's ashes to rest. The sun broke through the clouds as Tony quietly said a few words and then, unbeknown to us, read

FOOTPRINTS

One night a man had a dream.
He dreamed he was walking along the beach with the Lord.
Across the sky flashed scenes from his life.
For each scene, he noticed two sets of footprints in the sand;

one belonged to him, the other to the Lord.

When the last scene of his life flashed before him,
he looked back at the footprints in the sand.
He noticed that many times along the path of life
there was only one set of footprints.
He also noticed that it happened at the very lowest
and saddest times in his life.

This really bothered him and he questioned the Lord about it
“Lord, you said that once I decided to follow you,
You’d walk with me all the way.
But I have noticed that during the most troublesome times in my life,
there is only one set of footprints.
I don’t understand why when I needed you most you would leave me”.

The Lord replied, “My precious, precious child,
I love you and I would never leave you.
During your times of trial and suffering,
when you see only one set of footprints,
it was then that I carried you.”

✪✪

Although Zoe’s ashes are at the Crematorium the place that we feel the closest to her is at home. We have planted a rose garden just outside our kitchen window in her memory and it contains the many gifts of roses we have been given by family and friends (a pretty pink rose for our little girl on her first birthday, a white rose for Mother’s Day, and others named Superstar, Sweet Dream and Ray of Sunshine).

✪✪

Christmas, for us, will never be the same again. It feels very strange writing all the cards without including Zoe’s name. Although she is no longer with us she is still very much part of our family, yet it would be no longer correct to include her.

We spent the first Christmas day without Zoe at home on our own. Oliver’s enthusiasm carried us through Christmas morning but at lunch time our eyes were drawn to the empty space where the high chair should have been and the tears began. There were no words of comfort we could offer each other.

✪✪

There are constant reminders of our loss in every aspect of our lives. There seems to be prams, babies or pregnant women everywhere, and every other advertisement or programme on the television portrays a healthy, happy baby. Some songs remind me of Zoe, particularly Chris de Burgh’s “Carry Me”. Every month in the post, even to this day, we receive free samples of nappies, baby food or drink to suit her for the age that she should be now.

Whenever I see a little girl who was obviously born around the same time as Zoe I try to imagine what she would have looked like. Usually, though, I think of her still as a little baby, smiling and sucking madly on her two favourite

fingers.

We have photographs of Zoe all over the house. One portrait, taken at Oliver's playgroup, shows him pensively and protectively holding his little sister (before we knew she was ill). The photograph is enlarged and on canvas and it dominates our lounge.

We took many photographs of Zoe during her short life. One of my favourites was taken only five days before she died. She was giggling happily. It was very odd, later on, to collect developed films from the chemist and find no photos of Zoe amongst them.



One of the more difficult tasks I had to face following her death was returning to work, which I wanted to do fairly quickly to try and restore some sort of normality back into our lives. So, after a holiday, I recommenced my work on the Day Ward in the middle of May.

I come into contact with many different people during a normal working day but I was completely unprepared for the number of people who showed their concern to me. Some of them said nothing but patted my back or arm, some said how sorry they were, and some, who didn't know, asked me whether I had had a boy or a girl, or how she was. All of them made me cry at first, but I was very grateful for all their acknowledgements. As the weeks went by the amount of questions didn't cease but gradually I was able to talk more freely about Zoe. Now, nearly two years on, I am still asked about Zoe, but, as my colleagues will tell you, no-one can stop me talking about her now!

'Up and down' was a phrase I used often in response to the question "How are you?". It summed up exactly how I felt. Suddenly unexpected emotion could strike at the most inopportune moment and catch me completely by surprise. One example of this occurred eight months after Zoe had died. It was my dad's birthday and Keith, Oliver and I were all at my parents' house, along with my brother, his wife, and their two girls. My dad had his three grandchildren around him beside the cake, singing 'Happy Birthday' and, I suddenly realised that Zoe should be there too, helping her grandad blow out his birthday candles. The emotion, when it strikes, can be sudden and very forceful.



One of the questions I am never quite sure how to answer now is, "How many children do you have?". Zoe is, and always will be, part of our family, yet if I say 'two' I am obliged to explain (sometimes to complete strangers) that one of them is no longer with us. If I say 'one' I feel guilty as I feel I am denying that Zoe ever existed. It is a difficult question for bereaved parents and there is no right or wrong answer.



Zoe's short stay with us has definitely changed our lives for ever. We no longer take anything for granted and we realise how precious and vulnerable life is. I worry incessantly when Oliver is ill and my imagination runs riot. The one thing I thought could never happen to us, has, and we now know that there are no guarantees in life. We tend not to worry or argue about trivial matters and our whole perspective on life has altered. We spend more time relaxing and doing

what we want to do.



Zoe has made us smile several times since her death. Five months after she died we were on holiday in France and driving with friends through the flat French countryside in the rain. Suddenly the sun broke through the clouds and we were faced with a wonderful sight. An enormous rainbow, from beginning to end, glistening in all its glory - "I'm counting all the colours in the rainbow, checking that the sun's got a smile....." None of us had ever seen the complete arch of a rainbow before. We laughed, cried and remembered little Zoe.

Another incident occurred the week before our first Christmas without her. Each week we play the National Lottery and have two rows of numbers made up of all our birthdays. This particular Saturday morning Keith predicted, for the first time ever, that, "My Zoe's going to be lucky tonight!". As we watched the numbers being drawn that evening we could not believe our eyes. Zoe's entire date of birth, 23.8.94 (but 49) were in the winning combination, and one of Keith's numbers came up too, giving us four numbers in a row. It was a little Christmas present from Zoe and with the money we bought a little stone teddy bear to sit beside her roses in the garden.



One thing is certain for us now. Where ever we go, and what ever we do, there will always be one very special little girl missing. We will remember her every day for the rest of our lives, and think ourselves very lucky that she was ours, even though it was only for a very short time.

