

Ref : PB/MEL/JNH/10070825-0001  
Filed on behalf of : The Claimant  
Witness : Stevenson Paula  
Statement No : One  
Made : 5 November 2010

IN A PROPOSED MATTER

B E T W E E N:

**PAULA STEVENSON**  
(Personal Representative of the estate of  
**HAYLEY ELIZABETH FULLERTON Deceased**)

Claimant

-and-

**BIRMINGHAM CHILDREN'S HOSPITAL NHS**  
**FOUNDATION TRUST**

Defendant

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**WITNESS STATEMENT**

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I, **Paula Stevenson** of 24 Hollywell Road, Biggera Waters, Gold Coast, Queensland, Australia, QLD 4216 Will say:-

1. I live at the above address with my husband Bobby Fullerton. I make this statement following the death of my child Hayley. This statement summarises my concerns about the treatment my daughter received at the Birmingham Children's Hospital. I have a significant number of concerns in respect of Hayley's treatment and how my complaint has been managed by the Trust. But I have confined myself to the key issues in respect of the treatment only for the purposes of this statement.
2. Hayley was born on 6 October 2008 and passed away on 11 November 2009.
3. My daughter was born at Royal Victoria Hospital, Belfast, Northern Ireland with Pulmonary Atresia and VSD. She had to stay in Hospital for 9 and a half weeks following her birth. She had a planned operation on 1 December 2008 at the Royal Belfast Hospital. During this operation she had a shunt fitted in her heart to repair the hole. She was then referred to Birmingham Children's Hospital for further management by Dr Frank

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Casey because Dr Gladstone the Belfast surgeon was retiring. We were more than happy to stay in Belfast as we had a great relationship with all the team at the Clark Clinic and they treated us with respect and included us in all Hayley's care. It was a family focused ward, caring and professional. I was informed that I could either send Hayley to Dublin, Brisbane or Birmingham. I chose Birmingham because of its excellent reputation and I was thrilled to think that my daughter was going to be in the hands of the best experts in the UK.

4. Hayley was admitted to Ward 12 at the Birmingham Children's Hospital on 12 October 2009 for corrective heart surgery. The surgery took place on 14 October 2009 and it was performed by Dr William Brawn. The operation was a success and I was relieved.
5. Hayley then remained in the Pediatric Intensive Care Unit (PICU) until 31 November 2009. Hayley's stay in the PICU had to be extended because of two failed attempts to take her off the ventilator. A problem also arose when those treating Hayley attempted to insert a tube into her lungs. I was informed that the tube used was too long. An initial x-ray was taken which revealed no damage to her lung. However, 5 hours later, following another x-ray I was informed that Hayley's right lung had collapsed.
6. I discussed this incident with a number of people including Justine Kidd, the Cardiac Liaison Sister, Dr Adrian, the Clarke Clinic, who wondered why Hayley had been in PICU for so long, and I also informed the Ward 11 staff when Hayley was later transferred.
7. I specifically told Dr Adrian that I was not happy about the tube causing Hayley's lung to collapse but that I appreciated that sometimes mistakes can be made. I genuinely thought that it was an honest mistake. I made it clear that if the tube was to be inserted or

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removed again I would like a more senior member of the team to do it. I also asked if I could be present at the time. I was told that points were taken on board.

8. As a consequence of the collapsed lung the PICU then placed Hayley on C-Pap and kept a careful eye on her lungs. Hayley hated the mask and kept trying to pull it off so I started to stay with her overnight to pacify her as much as possible. She was not sleeping through the night at this stage and started pulling her hair out. It was horrible but I persevered and we got through it. I was very proud of my little girl.
  
9. On 31 October 2009 Hayley was discharged from PICU, we were all very excited and I was looking forward to being able to take Hayley back to Australia with me to be with my husband as a proper family. Before we left Dr Brawn came to my family and asked whether Hayley had ever had any respiratory problems in the past. I explained that she had never had a cough or a cold as I had been very cautious with her following her 9 and a half week stay in hospital after her birth. I also explained that Hayley was a very strong baby and was only in intensive care for 23 hours following her shunt operation.

Anyone who had any cold like symptoms was not allowed to come to the house. I did not take Hayley anywhere socially for 3 ½ months until 1 April 2009 when the flu season was over and then I took her everywhere to make up for lost time.

10. I got a feeling by what Dr Brawn was saying that he was unaware of the tube incident which collapsed Hayley's lung. It was not recorded in her notes. Despite this I was fond of everyone in the PICU and was really happy that Hayley was being discharged because Hayley was doing so well, I subsequently decided not to mention it as I did not want to get anyone in trouble or point fingers. Looking back I wish I had told him about the

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incident, but I did not want to cause any trouble as Hayley seemed to be recovering well and she was my only priority.

11. When Hayley was discharged from the PICU she was transferred to Ward 12 and I was told that she would be going into High Dependency. Hayley had the dressing on her wound changed before we left as it was a bit yellow and sticky. When we arrived on the ward Hayley was placed on the open ward. They said that she was actually next door to the high dependency unit but was closest to the nurse's station. I was a little apprehensive and worried but Hayley loved the open ward. She was so excited to be with the older children on the ward. It was lovely to see her being her normal bright and bubbly self again. She was a very nosey little girl and thrived in Ward 12.

12. On 1 November 2009 a nurse informed me that Hayley would have to move to Ward 11. I told her that Hayley absolutely loved Ward 12 and asked if there was anyway that we could stay. I was also confused as to why they wanted to move us as the day before they told me that she had to be on Ward 12 near to the nurse's desk. I explained that Hayley seemed settled for the first time in a while and asked if we could stay. I told the nurse "Hayley was supposed to be in High Dependency and that didn't happen and now you want to move her out of the ward altogether?" She agreed to let us stay. I was very grateful.

13. On 2 November 2009 the nurse told my mum that we would have to change wards again. I was at the hotel getting some rest but my mum rang me straight away to inform me. I immediately rang the ward to find out what was happening. Again, I explained that Hayley loved Ward 12 and that I had been told the day before that she was able to stay. I was really upset. I even cried which is really out of character for me but I knew how settled

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Hayley was and how well she was doing and I did not want anything to jeopardise that. She needed to stay on her HOME WARD, I was really worried if she was moved that no-one would know her history and she would slip through the cracks.

14. I was told that Hayley needed to go to Ward 11. I subsequently agreed to the transfer even though I wasn't happy about the situation. When I rang the Ward Manager on Ward 12, she promised me Hayley would be put in High Dependency in Ward 11. I was so excited. This was the first time since Hayley spent 16 days in PICU that she would finally receive the High Dependency care that they told me she would receive.

15. I returned to the Hospital at about 6.30 pm that evening and was horrified to find Hayley dumped at the door, the furthest away from the nurse's station. Hayley was not in High Dependency – The Ward Manager on Ward 12 had lied. I was extremely upset and felt as though Hayley was being punished and placed as far out of the way as possible because I was reluctant for her to be transferred to Ward 11. I felt as though I could not say anything to the staff on the ward because I did not want to cause any trouble and did not want Hayley to suffer because of my complaints. I felt Hayley was being punished because I spoke up. Hayley should be in High Dependency because she needed to be monitored carefully. Instead she was beside a child with no monitors and just establishing feeds to be sent home. Everyone knows closest to the door means according to the doctors you are the healthiest on the ward and are close to going home.

I hated Ward 11, Hayley was so far away from the nurse's station and barely monitored. No one took any notice of Hayley's monitors even when they alarmed. It was a common occurrence for the alarm to go off for 15 to 20 minutes and no one would come. The family made a decision that I would stay up with Hayley throughout the night and my

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parent's would stay with her during the day. We even flew Hayley's 19 year old cousin over to play with Hayley for 5 days because she seemed very unhappy in the ward. I was becoming increasingly worried about Hayley and tried to express my concerns to the staff but they did not seem interested. I even went out and bought one of the nurses a £100 gift voucher in a desperate attempt to bribe her to provide better care to Hayley. I hoped that the other staff would hear about it and also want to help her. I know it seems like a desperate thing to do, but I was desperate as no one was listening to me.

16. Hayley seemed to improve following her cousin's visit. At this point there were 4 of us looking after her and she loved the attention. Hayley started back on her bottle feeds, and was eating toast, Cheerios and beef stew. She was gaining weight and I was happy with her progress. She was even playing peek-a-boo with her bib. It was nice to see her playing and happily babbling away.
  
17. After a while I started to notice a deterioration in Hayley's condition. She had previously had a Staph wound in her chest incision and had been on oral antibiotics for over 11 days but her wound was not healing, in fact it was getting worse. The infected area was full of pus and had to be cut open by the surgical team.
  
18. On 6 November 2009 Hayley was started on a concentrated course of antibiotics in an attempt to shift the infection. Her oxygen levels were increased and we were informed that this was due to the fact that her body would be working harder to fight the infection. I immediately noticed a difference in Hayley. She went off her food, refused her bottle and became lethargic. All she seemed to do was sleep and she was really struggling to breathe. Her head was also bobbing. I asked those involved with her care if she was okay and whether she was suffering from an adverse reaction. Dr Ben Anderson

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informed me that she was merely resting more so that her body could fight the infection. I accepted this advice.

19. On 7 November 2009 Hayley's condition had become even worse. She was now sleeping all day and all night and her head bobbing had become worse. My mother and father both expressed their concerns to the medical team and told them about the head bobbing and the difficulties with breathing, but they were told that it had already been put in her notes. I was extremely concerned by this as when Hayley had been in Hospital in Belfast I was advised to constantly monitor Hayley's breathing and told that I should be aware of any changes in her breathing. The family were aware of changes in her breathing and my mother, father and I had all expressed our concerns yet nothing was done. It was very distressing to see my daughter like that.

20. My mother and father continued to express their concerns during the day and they kept being told that Hayley was just catching up on some sleep. My Mum even said to Dr Anderson that Hayley was a very poorly little girl. To this he responded that he had seen worse and that she had done well to get off C-Pap so quickly and recover from Pneumonia. The family were completely shocked by this as it was the first time we had heard that Hayley had pneumonia. My mum explained this to Dr Anderson and he provided a very brief explanation of pneumonia to my mum and then just said that Hayley was fine.

21. Mum and Dad were very concerned that Hayley was retaining fluid. She became very puffy. Mum said she felt like a cold hot water bottle. She felt heavy. This set alarm bells ringing as her mother had died of heart failure and retaining fluid was an obvious classic symptom of a failing heart.

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Hayley was a very small baby and it was really difficult to get her to put on any weight. She was only 5.8 kilos at age one despite being on a high calorie diet with fat boosting supplements. Mum and Dad asked all day to get her weighted. The nurses promised they would but didn't bother. The Clark Clinic were regimental about monitoring weight gain. Ward 11 didn't care despite the fact it was a specialist cardiac ward and Hayley was on diuretics. They were supposed to weigh her every other day but only weighed her twice in 9 days, then didn't update her weight on the daily Observation Charts. When the crash team was called, the nurse told the doctor working out Hayley's life-saving resuscitation drugs that she was 5.8 kilos. She was 6.31 kilos but the nurses were too lazy to update her 3 weight increases from 26 October 2009 to 11 November 2009. Hayley's drug was calculated on the wrong weight.

22. Although we were being assured that Hayley was fine it was obvious to me and my parents that she was really struggling to breathe. Even a complete stranger who saw Hayley said that she was struggling with every breath. We were very upset that a complete stranger could see that Hayley was in difficulty but the medical professionals merely said that she was fine. We could also see that Hayley was in trouble.

23. That night I continued to express my concerns and when the staff changed over at 8 pm I told a member of the support personnel about Hayley's lung collapsing in PICU and explained that she was still vulnerable. She then checked Hayley and again told me that she was fine. I was so confused. The Clarke Clinic had always warned me to look out for differences in Hayley's breathing and communicate them. I always felt as though my opinion was valued because a mother knows her child the best, whereas here my concerns were just ignored. It was so painful to watch Hayley head bobbing around and her struggling to breathe.

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24. On 9 November 2009 Mr Stumper was doing his ward round, Dr Anderson told Mr Stumper that Hayley was fine. By this stage the whole family were worried sick that our concerns were not being taken seriously and my father stood up and stated that Hayley was clearly not fine. My Father is not usually the type of man to interfere with people or interrupt people but we were all so worried and concerned that we were resulting to desperate measures. My Mum also asked whether there was a problem with Hayley's lungs. My mum spoke up "her lungs, her lungs, I'm embarrassed asking about her lungs". Dr Stumper listened to her chest and said it was fine and that it was clear.
25. The family continued to express their concerns and eventually an x-ray was arranged. The x-ray was taken between 2.00 pm and 2.30 pm. No one came to the ward until approximately 6.00 pm when the SHO then stood in the doorway of the room and did not enter the room. My mother and father were informed that Hayley had a collapse in her upper right lung. They said that they were not overly worried about it and that there was no need for concern. They advised us that Hayley's gases were fine and that they would organise physiotherapy for her but they did not say when. They just walked off, leaving my parents feeling upset and even more worried.
26. When my father informed me about Hayley's lung I was worried and upset that it had taken so long for us to find out about her lung bearing in mind that we had been complaining about her breathing and general condition for days. I was also appalled that the SHO did not even have the decency to explain the finding to my mother and father in detail and merely stood in the doorway and then left when she had explained the findings. I was so upset but all I was bothered about was getting physiotherapy arranged for Hayley as soon as possible. My Dad then asked when it would start and we were told that she could wait until the morning. I was furious as she had already been left for too long but I said nothing as I did not want to cause a fuss. The last time I caused a fuss

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Hayley was dumped at the door. I was scared to go and demand Hayley's physio straight away. I wish I had.

27. My father and I were also getting very agitated about the state of Hayley's wound and the lack of care of it. We were worried that her dressing was not being changed often enough. It was only being done once per day and it was becoming nasty looking. We expressed our concerns and the wound had to be opened by the surgical team for the second time. My father was constantly asking for the dressing to be changed but it was still only changed once per day. Although ideally it needed to be changed much more often as it was becoming soaked with pus. The top half of the wound was healing well and we were concerned that dressing covered in pus would cause that part of the wound to become infected also. My father was becoming so frustrated that again no one was listening that he asked for a special note to be made requesting that the dressing be changed at least twice per day. Every time he asked for it to be changed, the nurses would tell him they couldn't do it until the wound lady came (Tissue Viability).

28. On 23 October 2009 while Hayley was in PICU, we tried to get the Tissue Viability lady to review Hayley's nappy rash. I had followed hospital policy for 11 days and Hayley's bottom was red and angry. She was whimpering in pain. I asked if I could use Sudocrem to soothe Hayley's nappy rash.

Lisa Poole staff nurse told me that Lisa, Tissue Viability said it wasn't worth her while seeing Hayley if we were unlikely to change our minds about using Sudocrem. I felt really pressurised and guilty. The Tissue Viability lady, Lisa would only see Hayley if I had a re-think about following Hospital Policy. I always used Sudocrem and Hayley never had a rash. It was only when I stopped using it that her rash developed. Lisa from

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Tissue Viability refused to see Hayley despite her chest wound becoming more and more aggressive.

29. For the rest of the day, Hayley slept. She hardly opened her eyes and refused her bottle. We had to feed her through her nasal tube by gravity feed. She just laid there and struggled to breathe. She did wake up once and guzzled 30-40ml of water in one go which was extremely unusual for her.
30. At the time of staff change over at 8 pm Staff Nurse Hayley Stretton took over and she was like a breath of fresh air. I explained about Hayley's breathing difficulties and she was understanding and checked her at the start of the night and regularly through the night. I was so relieved that someone had finally started to listen to me.
31. At about 1.30am the following morning I gave Hayley her gravity feed because she was too exhausted to have her bottle. She also guzzled 30ml of water. I gave her the gravity feed whilst she was sat on my lap as I was able to give it to her slowly. However, when I placed Hayley back in to the bed she vomited. I cleaned her up and noticed that her breathing had started to become noticeably worse. I called for the Staff Nurse, Hayley and she fetched the SHO Pam Dawson who acted very quickly. An x-ray was organised and PICU was contacted. The x-ray team initially asked if Hayley could be transferred down to the x-ray department but Pam told them that Hayley was in severe respiratory distress and that they needed to get to Ward 11 immediately.
32. The first x-ray failed so another had to be taken. Hayley was then placed in a head box with 5 litres of oxygen, IV fluids were set up and we were instructed that Hayley was now nil by mouth. Pam showed me the x-ray and compared it to the x-ray that had been taken

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earlier in the day. I was so shocked by the difference in the two x-rays. There was a massive difference. I could see that from the first x-ray a small part of the upper right lung had collapsed but the second x-ray looked as though the whole lung was now affected. Pam told me that the lung was full of gunk and that there were hardly any black areas of the x-ray which would explain why Hayley was struggling to breathe. She also informed me that Hayley's left lung had also been compromised. I was so shocked by what I was hearing and I could not believe that Hayley had just been left to deteriorate.

33. Pam informed me that PICU advised her that Hayley would need a hell of a lot of physiotherapy. I asked Pam to ring PICU and get them ready for Hayley and she informed me that she would speak to her senior and not to worry, PICU was always ready. Pam rang around to get a physiotherapist at 2.30 am to get help for Hayley straight away but despite Pam's efforts no one came until 8.30am.

34. I could not believe what was happening. All along the family had expressed their concerns about Hayley's breathing and had even asked if there was a problem with her lungs yet nothing was done. Even when an x-ray was taken which indicated that Hayley's lung had begun to collapse still nothing was done. It was bad enough ignoring us but they ignored the medical evidence. I knew Hayley was in serious DANGER.

35. Hayley was kept in the head box with 5 litres of oxygen. I stroked her head as much as I could to try and comfort her but I wanted to make sure that her oxygen levels stayed up so I had to shut the porthole in the head box. I missed my little girl so much. All she did was sleep, she was so weak and I felt as though I had not seen her eyes in so long. I felt so let down by everyone involved in Hayley's care and I felt as though I needed to start

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speaking up for my baby to ensure that she got the help she needed in order to get better. I no longer trusted anyone on Ward 11 except SHO Pam Dawson.

36. I was becoming desperate. I am usually quite a strong and focussed person but what was happening to Hayley was destroying me. I knew I needed to do everything possible to help my daughter.

37. At approximately 8.00 am that morning I informed my mum about Hayley's lung and she said that she was not surprised. I kept her text "I have been asking and asking about her lungs; doctors, nurses, everyone. Not surprised". We had known all along that something was seriously wrong with Hayley's lungs and my mother had even specifically asked about her lungs but we were told that her chest was clear. I do not understand how things were left to get so bad.

38. At 8.30 am the physiotherapist arrived and I was relieved. I was out of my mind with worry and literally thanked god that someone was there to help. I was so upset and exhausted that I told them that I felt that no one cared about Hayley and that the family had seen her deteriorate and raised our concerns but that no one had taken a blind bit of notice to us. My mum kept asking about Hayley's lungs and we were constantly told that she was fine. Physio wrote in the medical notes "mum very concerned".

39. Hayley then had 1 session of physiotherapy and became a lot more comfortable and it helped with her breathing. The Physiotherapist arranged to come back at 13.30.

40. At shift handover I told the new staff nurse Sanjit Moore what had happened that night. I explained that Hayley had been neglected and was not receiving proper care. Sanjit was

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wonderful and went straight to the Ward Manager, Jacqui Clinton. Jacqui then asked if I wanted to make a formal complaint. At the time I told them that I did not want to make a complaint and that I just wanted them to help Hayley to get better. I did not want to waste my time completing the documentation when Hayley needed me. I was putting all of my energy to looking after her and making sure she as cared for by the medical staff. Looking back I wish I had made the formal complaint as maybe it would have changed the dreadful outcome for Hayley. Jacqui would have taken me seriously and actually done something to help Hayley.

41. Sanjit continued to make every effort to tend to Hayley's needs throughout the day and I feel that she went above and beyond to try and make me feel better. Later that day I also saw Registrar Zdenka Reinhardt and told her that Hayley was in a terrible state and that I believed that she had been neglected. Zdenka was very kind and apologised. She told me that Hayley's wound infection was their number one priority and she would organise extra support for Hayley. Again, I was relieved that finally something was being done. I thought that the extra support would mean that we would finally be moved to the PICU or at least the high dependency, but I was wrong. Mum remembers her saying Hayley might have to be moved back to PICU and this might be perceived as a step backwards.

42. I asked Dad to get Junior Sister Sheila Bennett to come and look at Hayley. Despite still being on Ward 11, I was starting to feel more comforted as by this stage everyone was starting to rally around and help Hayley. Sheila Bennett removed Hayley's nasal prongs. I couldn't believe that not one of the medical team had the brains to remove the nasal prongs. They had no oxygen connected and impaired her breathing. Sheila stuck down her NG tube and helped us fix Hayley's IV fluid line because it kept occluding. Hayley was always having problems with her lines. I kept telling everyone that she required a

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brovine line as when she was in Belfast it sometimes took over an hour to put the lines in and 9 times out of 10 they had to call for someone who was more senior and experienced to ensure that it was done correctly. By this point Hayley's left ankle was swollen and puffy from where the IV Fluids had collected where her line had failed. We had to repeatedly ask both Sheila and Sanjit to help us fix Hayley's lines.

43. At 1.00 pm that day, my father and I saw Sheila talking to Sanjit and Simone, a student nurse about Hayley. The conversation looked serious and then I suddenly saw them reach for an isolation sign. They turned it around and shut the door before walking off. Sanjit then came into the room wearing a plastic apron, she told us that they were worried about infection and mentioned something about swine flu. An MPA swab had to be taken and we were told that we were to remain in isolation and not to enter the communal areas. We did as we were told. Sanjit didn't take the MPA swab until 6.30 pm, five and a half hours later. Sanjit told us that staff and the patient normally wear masks but they didn't – this was against hospital policy.

44. As soon as Hayley was placed in isolation, all of those who were tending to her needs tailed off. Jacqui Clinton disappeared as did all the doctors. She was now even more vulnerable. We had also been told that we were not supposed to leave the room. We were therefore unsure of how we were supposed to go and get help when it was required. Also as the door was shut, so we wondered how anyone would hear the alarm. I was very concerned. I was so confused about why Hayley had been put in to isolation and no one was explaining why. I recall bumping in to Sanjit the day after Hayley died and she said that she was told that Hayley had a cough and cold and that was why she was put into isolation. Hayley did not have a cough or a cold and therefore I still do not know why she was put in isolation. Again this made me wonder whether my constant pleas for help had caused Hayley to be put in isolation in an attempt to shut me up.

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When SHO Pam Dawson came on nightshift, the first thing she said was "What the hell are you doing in ISOLATION". I was alarmed.

45. I talked to Pam to try and establish why Hayley was in isolation. I told her I felt as though Hayley was being punished because I had told people that she had been neglected. Pam then went to check Hayley's notes for me and confirmed that she had made an entry telling staff to look out for symptoms of swine flu. Pam explained that there was a case of swine flu on the leukaemia ward and therefore they needed to be careful. I trusted what Pam said to me, but I still felt uneasy about the situation.

46. At 1.30 pm I saw the physiotherapist come up to the door of the room. They looked at the isolation sign and turned around and walked off. I was gutted. At 3pm I decided to go to the nurse's station and ask whether Hayley was being left to last for physiotherapy because she was in isolation. Sanjit explained that she would beep them straight away for me. I was starting to panic about Hayley being shut in ISOLATION.

47. At 3.10 pm a member of the surgical team came to cut open Hayley's wound again. Sanjit was shocked by what she saw and confirmed that she had never seen such a bad wound infection. Dr Stumper then came into the room and asked if the wound had got better or worse. I was not sure as my dad knew more about her wound so I asked him. It looked awful but it was not as red on the outside. There was supposed to be a wound care chart attached to Hayley's notes so I was surprised that they were unaware of how the wound was. I wish I had taken pictures of it now.

48. When Mr Stumper was looking at Hayley's wound my mum jumped up and asked him how her lungs were. He then glared at her and said "physio". My mum then asked if that

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will make it better and he shouted "yes physio" before leaving. We were all shocked by Dr Stumper's behaviour and my mum was upset by Dr Stumper's look of utter contempt. He was arrogant, rude and evasive. He acted like a child having a tantrum. No one in the Clark Clinic acted in that way. He was very unprofessional. This frightened us.

49. At 3.20 Hayley finally had another session of physiotherapy, which went well.
50. Throughout the day I kept noticing that Hayley's line kept occluding. It was happening at least 4 times per hour and we were trying our best to fix it ourselves as we were told that we were not allowed to go out of the room as we were in isolation. We all took it in turns to go out and ask for help. We were all very concerned that being in isolation was seriously jeopardising Hayley's access to immediate help and support because we were scared to leave the room and felt like we were being burdens to the staff when we asked for help. Hayley was therefore very vulnerable.
51. On 10 November 2009 there were tests done on Hayley but no one came to tell us any results. My mum and dad waited a long time for someone to explain the finding or what was going on, but as no one came, at approximately 5.30 pm my mum went over to the nurse's station and asked if Hayley's results were back. We appreciate that hospitals are busy places but we thought that it was unusual and unacceptable that we had not been informed of the findings. When my mum asked, the SHO stretched out her arm like she was stopping traffic and stated that she was busy and had to do something else. Another member of staff then rolled their eyes at my mum. She was treated very badly. Later on the SHO came to the ward door, opened it and muttered something about some results being up but there was nothing to worry about and off she went. The same as the night before.

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Later on at approximately 7.30 pm to 8.00 pm that day, SHO Niddi came to the door of the room but did not come in. She told me that Hayley's lung condition was not serious. I told her that Hayley was lying with her head in a box and was in a complete mess and that it should never have gotten to that stage. I told her that I no longer had any trust in the hospital. She then walked off explaining that she needed to organize the handover. I was not surprised. Everyone had turned their back on Hayley so far, this was no different. I told her this and she then came back to me and kept apologizing. She then came into the room and knelt down on the floor. I asked her to get up and speak to me like an adult. I explained that I felt my concerns had been dismissed and that we had been treated very poorly. She tried her best to apologize but by this stage I felt that it was too late and I said that she could leave, so she could organize the shift handover.

52. At 8.00 pm the same SHO came back after handover. I over compensated and was extremely friendly to her because now I was thinking "oh my God, all I've done is alienate the only person who could help her". She told me Hayley was getting antibiotics to prevent any infection in her lungs, I said I was happy and relieved about that. She mentioned that Hayley's infection count had doubled; her CPA had increased from 29 to 60. I didn't really understand CPA's but it sounded serious.

53. At the 8.00 pm – 8.30 pm handover I told the new staff nurse that Hayley had been neglected and I was really worried about her. I said I hadn't slept in 28 hours because I didn't trust the hospital. I was worried because we were in ISOLATION and I was scared I was going to fall asleep and not hear Hayley's monitor go off. The staff nurse offered to put the monitor outside in the corridor; that worried me even more because from past experience the monitor would go off for 15-20 minutes and no one checked it. As I had my own business, I was used to long hours and working all weekend without sleep was a regular occurrence for me, so I told her to just keep the monitor in the room.

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I told the nurse I was worried about Hayley's line as it was occluding all day and she wasn't getting the fluids she needed. I asked about starting her back on milk feeds, she said she would have to get the doctor. She told me I should have organised it during the day when the doctors were on the ward. I got annoyed and said Hayley wasn't getting her proper fluids, I had talked to the day staff about her milk and I didn't think it would be an issue. She said she could beep the doctors but they wouldn't like it as it was only for emergency. She was being sarcastic. I said of course I don't want you to beep the doctors that would be stupid. Hayley had an emergency last night when her lungs collapsed that was a serious situation; that is when you get the doctors. "Don't make me out like I'm being a bitch, of course I wouldn't dream of disturbing the doctors". I was worried about being labelled a bitch when I started speaking up. I worried about how that would impact on the quality of Hayley's care. I was scared now. When she came back from talking to the doctors, I bent over backwards being nice to her. I was EXHAUSTED being on high alert to get Hayley help and having to be nice to people I didn't have faith in.

54. At 12.00 midnight, I went to the nurse's station to tell staff nurse to put a new water bottle in for Hayley's vapour/oxygen tube which she did straight away. I saw Pam Dawson and gave her a big hug, thanking her for looking after Hayley. I said I was glad that she and staff nurse Hayley were there in the early hours of Tuesday morning and I was really, really grateful to them both.

Dr Zdenka was at the nurse's station and asked me how Hayley was, she was very kind. I told her Hayley was a lot brighter after physio and that she was looking good. I apologised for jumping down her throat earlier on but explained that I was just really scared. She told me "you have to speak up for your baby". I FELT A LOT SAFER. She

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then asked me how I was, I rolled my eyes and said I was better and we both had a giggle.

All through Tuesday night, I kept an eye on Hayley, kept clearing water from her tube and wiping the excess from the inside of her head box. The oxygen indicator inside the box showed 39-43 %.

At 7.00 am on 11 November 2009, Hayley was put back on 100 % milk feed. The medical notes however, state Hayley was put on 100 ml/kg continuous at 2.00 am. I was not informed. I had no idea. The staff nurse did not tell me. Hayley's stats dropped from 93 to 88. Her alarm sounded for 15 minutes but nobody came.

55. At 8.30 pm the new antibiotics were administered. Hayley was given half IV fluids and half milk and after the nurse rang SHO Pam Dawson, observations were back on every hour.

56. Throughout the night I kept a close eye on Hayley and did not go to sleep at all. I kept clearing water from her tube and wiping the excess from the inside of her head box. The oxygen indicator inside her box showed 39-43%.

57. At 7am the following morning Hayley was put back on 100% milk feed and her SATS dropped from 93 to 88. Her alarm sounded for 15 minutes but nobody came. At 7.15am I got the staff nurse to stop Hayley's milk feed as she had to work harder to breathe. It took

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15 minutes to get her SATS back up. Pam then came to review Hayley and could see that she had to work harder so she put her back on half IV and half milk.

58. At 7.30am the new staff arrived for the handover. I always like the changeover in the morning as there was a new energy and fresh faces and it was noisier. I had not slept in 38 hours but I knew that my mum and dad were due to arrive at 9.30 so I would be relieved. At that moment I glanced at myself in the mirror realising how horrendous and exhausted I looked. I grabbed my wash bag but then put it down again as I decided that I did not want to leave Hayley alone in the room with the door shut. As I put the bag down I realised that I had taken my eye off Hayley for a split second and I had a dreadful feeling.

59. I turned around in the room and saw that Hayley was really gasping for breath. Her SATS suddenly dropped to 65. The left side of her mouth puckered out but the right hand side was completely sucked in. Her eyes were panic stricken and they started rolling back in her head. I could see that her neck was starting to collapse in. At first I thought she was choking so I took her head box off and put her on my lap to pat her on the back. I knew within seconds that she was in serious trouble so I put her back on the bed with the oxygen pipe under her nose but it was not given her any relief.

60. I cried for help but nobody heard me. The door was shut because we were in isolation. I knew I had to leave Hayley to go and get help but I felt sick. She was scared and struggling to breathe and I was running off. Within seconds I had Hayley back on the bed and put her head box back on, attached the tube and ran for the nurses who came straight away. One nurse started to put the oxygen mask on and the other said 'oh dear' and rang PICU. They tilted Hayley's head back to open up her airways. She looked awful, like a fish out of water gasping for breath. She then started turning blue. She was in so

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much trouble and I knew that she needed help. I was worried that because we were in isolation that we would not be able to go to the PICU. I was terrified that they would all have to put plastic aprons on and follow isolation protocol. Hayley was in terrible trouble and every second counted. I wish I had never let Sheila Bennett put Hayley in isolation. PICU ran into the room and they didn't bother with the aprons. Thank God.

61. There were about 15 people in the room all trying to help Hayley. I recognised Dr Rich. When he went to put the long tube down Hayley's throat he noticed that Hayley's new front teeth, it was the first time I had seen them. Dr Rich then asked for adrenaline, I knew that her line had failed because I heard someone say something about it being out. I was always worried about Hayley's lines and now that she was in serious trouble I feared for her life. Every time Dr Rich called for adrenaline, Dr Zdenka tried to administer the medication but it kept squirting out into my face. I think this happened 4 or 5 times. I was petrified that it was not getting to Hayley's heart.

62. The team frantically tried to put Hayley's lines in. All of the time I was stroking her head and telling her that she was the best girl in the worlds. About 8 different people took it in turns to try and resuscitate Hayley. They worked on her chest until their hands hurt. All the time the colour was draining from her body and she looked helpless.

63. I could see the monitor flashing red 'cardiac arrest' and her hand became limp. I kept squeezing her hand to see if she would respond. Her wound was leaking pus everywhere from the pressure of the resuscitation. She never squeezed my hand back it was cold and lifeless.

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64. They then took the bars off the top of the bed. I helped to pass it out of the room and checked that there was nothing under the bed so that she could be transferred to PICU. I grabbed my little girl's hand and kept speaking to her. I really wished that we were in PICU as there was so much more support. I was so angry with myself and the staff on Ward 11. They were useless.

65. After 15 minutes Jacqui Clinton came in and asked if there was anyone she could call. She had to come back as they didn't have telephone numbers recorded for Mum and Dad. It was the first time I had seen Jacqui after I told her I didn't want to complain. I just wanted her to save my baby. She did nothing to help Hayley. She couldn't even call Mum and Dad. I was so angry.

After 17 minutes they stopped working on Hayley and checked her vitals. At this point I asked the doctor how long we had for brain activity and he said that they still had time, so they resumed the resuscitation. I believe Dr Rich was just trying to be kind.

66. At 18 minutes the doctor said that he could feel Hayley's heart and then suddenly numbers appeared on the monitor. It felt like the lotto. Then all of a sudden he said something about a collapse. I leant forward and asked him "what do you mean collapse?" He turned his head away. He couldn't answer me. He couldn't even look at me. He just kept giving Hayley chest compressions.

67. At 19 minutes I noticed that everyone had stopped looking at Hayley and they were now all looking at me with pity in their eyes. I also noticed that Hayley had soiled her nappy. The same doctor who couldn't look at me started speaking to Hayley and said come on sweetheart while he worked on her.

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68. At 20 minutes Adrian put his hand on my back and confirmed my worst fear. He said "sorry mum, we have lost her". All I could think about was how I was no longer a mummy because my only child was dead. I was in shock and utterly devastated and absolutely furious. How could Ward 11 have failed Hayley so disgustingly?
69. All the Crash Team took all the leads and lines off Hayley very quickly.

I wanted to thank PICU staff as they were professional and caring but I also was livid at the Ward 11 staff. My family and I had warned them and still they did nothing to help Hayley. They had allowed her to die shut in isolation and abandoned on the ward like an animal until she had a cardiac arrest.

I worded my thank you carefully. I wanted to see how Ward 11 staff would react. I was setting a trap. "Thank you for doing your best for Hayley, I really appreciate all your efforts". Dr Zdenka was at the sink washing her hands. She looked me in the eye absolutely horrified. Her face crumpled and she started screeching/wailing and fell forward and threw her arms around Dr Rich and had to be dragged out of the room. My worst fears and suspicions were confirmed by her reaction. She promised Hayley extra support but then she was put in Isolation. She informed me Hayley might be put back in Intensive Care but didn't even put her in High Dependency. She told me at midnight the start of a new day 11 November 2009 "to speak up for my baby". Eight hours and fifteen minutes later, Hayley was dead.

After I thanked PICU, they asked if they could do anything to help. I asked them to leave me alone with my daughter and switch the lights off in the room as Hayley always hated bright lights. I picked her up into my arms and wrapped her in her bunny blanket. I then

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called my husband Bobby in Australia and told him that his baby girl was dead. I put the phone to Hayley's ear so he would tell her he loved her and say goodbye while she was still warm.

70. I believe very strongly that Hayley's death could have been prevented. I truly believe that if the medical team had listened to me and my parents, she would still be alive today. They turned their backs on her.
71. I was informed that the Hospital would take care of Hayley after her death but I refused. I explained that I did not want the hospital to touch my daughter as I had lost all faith in them and did not trust them. I explained that I wanted someone who was independent to look after her. Hayley was neglected and overlooked when she was alive and suffered considerably as a result. I did not want her to be neglected and overlooked now that she was dead.
72. I expressed my concerns to all of the staff on Ward 11 after Hayley's death and demanded answers, but no one could explain. I even spoke with Dr Ben Anderson and asked him why nothing had been done sooner and again he said that Hayley was fine. His words failed me. I could not believe that he was still insisting that Hayley was fine when she had passed away. I said to him that Hayley had died and that she could not have been fine and he did not offer any condolences or sympathy.
73. There was however, one member of staff at the hospital who stated that they accepted my criticism when I stated there was no need for Hayley to die. She apologised but she was the only one. I did not reveal her identify as I didn't want her to be made a scapegoat. She was young and inexperienced and was only following orders and taking

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direction from her seniors who should have recognised classic signs of heart failure. They were the professionals after all and had all the extra years experience. That is why I took Hayley to Birmingham because they boasted they were the 'Centre of Excellence'. In May 2010, I found out she no longer worked at BCH. So now I can tell you, it was SHO Niddi.

74. I cannot begin to explain this impact that this has had on myself and my family. My husband flew over to England when he heard the news and when he arrived all I had to offer him was the baby grow that Hayley was wearing at the time of her death and a lock of her hair. Both Bobby and I are devastated. Hayley's experience at Birmingham Children's Hospital can only be described as BRUTAL.

75. My mother was also massively affected by her granddaughter's death and she has not been the same person since. She is withdrawn and spend a lot of time in bed whereas she used to be a very active and sociable person. She and my father are utterly heart broken by what has happened and we are all determined to fight for justice for Hayley. We want to send a clear message to all medical staff that it is vital to listen to the family's concerns as they know their child better than anybody else and to ignore these pleas is dangerous. It is also socially, morally and ethically wrong. "The first rule of paediatricians is always, listen to the mother – if they are concerned so should you be". These people are trained to listen for crying out loud.

76. The matters referred to in this witness statement are within my own knowledge except where stated otherwise.

77. I believe that the facts stated in this witness statement are true.

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