

Hayley Elizabeth Fullerton

06/10/2008 - 11/11/2009



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# **OFFICIAL COMPLAINT LETTER**

**16<sup>TH</sup> DECEMBER 2009**

**RE: NHS COMPLAINT  
HAYLEY ELIZABETH FULLERTON  
06/10/08 – 11/11/09**

Please ignore letter dated 17<sup>th</sup> November 2009.  
This was forwarded without my permission by  
Alison Stanton, Patient Relations Manager

## **IMPORTANT**

**Please note – I did not receive the medical records until 15<sup>th</sup> January 2010. I wrote the official complaint letter 16<sup>th</sup> Dec 2009 with no knowledge of what was in the medical notes.**

**I have highlighted medical updates and additional comments in RED.**

PRIVATE & CONFIDENTIAL

Birmingham Children's Hospital NHS Trust  
Steelhouse Lane  
Birmingham  
B4 6NH

16<sup>th</sup> December 2009

To Whom It May Concern

**RE: NHS Complaint – Hayley Elizabeth Fullerton, 06/10/08 – 11/11/09**

I am writing on behalf of my only child Hayley Elizabeth Fullerton who died at 7.50am on Wednesday 11<sup>th</sup> November 2009. She died in Ward 11 at Birmingham Children's Hospital in the room located next to the door.

Hayley died 28 days after her corrective heart surgery.

I am writing to complain about the serious lack of duty of care towards my baby. I believe Hayley was "Overlooked, Neglected and there was no need for her to die". I kept repeating my belief to as many of the medical team as I could after Hayley died. Only one person admitted the truth when I told them "Hayley had been overlooked, neglected and there was no need for her to die" they started crying and said "I'm so sorry, I completely accept your criticism", I was so shocked when I found out Hayley had died, I completely accept your criticism".

I want a full investigation to be carried out.

**BIRMINGHAM CHILDREN'S HOSPITAL ROOT CAUSE ANALYSIS OUTCOME**

**Early commencement of Pressure Support Ventilation of this patient, could have prevented the patient's death.**

## HAYLEY'S HISTORY LEADING UP TO PERIOD OF NEGLECT

12/10/09:

Hayley was admitted to BCH for corrective heart surgery, Ward 12.

14/10/09:

Dr William Brawn performed corrective heart surgery. He did an amazing job.

14/10/09 – 31/10/09: PICU

PICU - overall treatment was excellent.

One problem, they had accidentally collapsed Hayley's upper right lung. The long tube was one millimetre too long; **\*Medical notes confirm it was 5ml too long. 19/10/09 – 12:45 Bal performed. ETT pulled back to 14cm.** It was a genuine mistake and PICU did their best to rectify it. Hayley had to be given extra support to fix her lung problem which resulted in an extended stay of 16 days in PICU. Hayley had two failed attempts to take her off the ventilator but she finally made it out onto the ward. I was very proud of my little girl.

31/10/09 – 02/11/09:

Hayley was transferred to Ward 12; she was supposed to be in High Dependency but was put in the open ward closest to the nurse's station.

**Ward 12 blamed me for Hayley not being put in High Dependency!  
Birmingham Children's Hospital – RCA Outcome.**

**"The patient and mother were offered one of the beds in the high dependency area within Ward 11. Beds in the high dependency area have room for a chair next to them for family members but do not have room for a parental bed. The patient's mother wanted to have a bed alongside her daughter, therefore it was not possible to accommodate the mother's wishes whilst nursing the patient in a high dependency bed, and this is the reason why the patient's transfer was delayed from Ward 12".**

**This is a total fabrication. I slept in the hotel during the day so I could keep watch over Hayley at night. I sat in a chair in PICU for 27 hours straight. I would never put my comfort above the safety of my child.**

**"It was noted by the review team that the patient's mother was not happy about the bed allocation".**

**My parents and I organised 24 hour bedside watch for Hayley as I was so concerned about her not being in High Dependency. Mum and Dad did days and I came in at 6.30 pm at night and stayed until 9.30/10.00 am the following morning.**

**The MEDICAL NOTES CONFIRM THIS.**

02/11/09 – 11/11/09:

Hayley was transferred to Ward 11, I was promised again she would be in High Dependency but she was put in the room next to the door and furthest away from the nurses' station. Nobody really had the time to get to grips with Hayley's medical history because she missed out on the High Dependency experience. The staff were busy looking after the priority patients but Hayley was the one left to die.

### **HAYLEY'S CONDITION SUDDENLY AND DRASTICALLY DETERIORATED**

Dates of decline: Friday 06/11/09 – Wednesday 11/11/09

The medical team on Ward 11 did not respond appropriately to the concerned pleas of Hayley's immediate family that something was seriously wrong. I told the staff I refused to leave her side because she wasn't getting the help she needed. They told me to rest, I said "how can I rest when my child is suffering?" I didn't sleep for 38 hours before Hayley died.

24 hours before Hayley died:

I told the medical team on Ward 11 that Hayley had been OVERLOOKED and NEGLECTED. They knew her lung was collapsing but organised physio too late. Both lungs collapsed because they did not act fast enough. \* Medical notes confirm – Massive consolidation left lung, volume loss right lung. 09/11/09 – 18:00. Plan Physio 10/11/09. The notes did not indicate that physio was required urgently as a result of the x-ray result.

Telephone Conference – 28 July 2010

I asked Dr Stumper, Head Cardiologist why Hayley's physio was deferred. His excuse just adds INSULT TO INJURY. He told the SHO Niddi – "this child needs physio and I didn't specify this child needs physio the same evening, having said that, I was somewhat horrified in the context of the x-ray that the physio wasn't involved on the same evening but it is true, I did not specifically request, having said that, I would have expected people to act upon an x-ray which was really quite bad at the time".

"I think I admit erm that possibly because my – lets say general instructions to get physio involved and without stating tonight or immediate, erm I think that was an omission and I have certainly learned to be more specific. I thought some things can be transmitted – NON VERBALLY".

22 hours before Hayley died:

Ward Manager Jackie Clinton asked me if I wanted to make a FORMAL COMPLAINT. I told Jackie I didn't want to leave my baby to fill out complaint forms; I just wanted everyone to listen and to HELP HAYLEY

It's only now a year later after going through medical notes, talking to doctors, looking up hospital guidelines etc etc, that I realise Jacqui Clinton was more concerned with de-escalating a complaint than the terrible state Hayley was in. How could I have been so stupid?

She sounded sincere enough but her response to my fears for Hayley should have set alarm bells ringing.

She didn't even look at Hayley, she was more concerned with red tape.

If a mother is that scared for her child's welfare, and she is forced to confront the hospital and accuse them of neglect, the least she could have done was look at Hayley.

If she did, she would have seen that Hayley still had the nasal prongs stuffed up her nose, despite the fact that they were not connected to an air supply, because Hayley was in a head box with 4 litres of oxygen pumping in it, because they allowed Hayley's lung to collapse.

Jacqui put a student nurse in charge of Hayley but told the Review Panel, Hayley received High Dependency Care. Then disappeared.

Her staff were lazy and incompetent. The staff nurse Jane Titley on Hayley's last shift didn't take Hayley's temperature for 9 hours straight and she was supposed to have the Swine Flu.

She wrote in her notes, Hayley was on 0.3 litres of oxygen nasal prongs when 2/3rds of her body was covered with a head box pumping 4 litres of oxygen.

Hayley had steadily increased from 0.3, 0.5, 0.75 and 4 litres of oxygen over 7 days but Jane Titley just wrote what the nurse before had written.

The nurses were supposed to weight Hayley every other day but only weighed her twice in 9 days.

They kept writing alternative days, alternate days instead of weighting her.

They were excited Hayley was gaining so much weight on Monday 9 November 2009.

Despite Hayley's Granny asking, was fluid retention caused by heart failure (her mother died of heart failure so she knew the warning signs), they failed to realise Hayley was slowly drowning in her own bodily fluid.

This was a specialised CARDIAC UNIT for crying out loud.

Fluid retention is a classic symptom of heart failure. When the Crash Team came, they calculated Hayley's meds on the last weight recorded. The notes said 5.8 kg. They didn't bother recording Hayley's 3 weight increases.



Hayley was supposed to be on hourly observation since her lung collapsed but only received 14 checks out of 30.

The nurses failed completely to give Hayley her evening meds 3 nights in a row just before she died.

But Jacqui Clinton insisted that Hayley received High Dependency Care.

According to;

Nursing Issues: STAFFING, EDUCATION AND TRAINING FOR HIGH DEPENDENCY CARE.

### Expertise and Supervision

A registered children's nurse, who has completed an advanced life support course eg PLS/APLS/PALS, should be present at all times throughout every 24 hours period.

### 19 hours before Hayley died:

Junior Sister Sheila Bennett put us in ISOLATION; she told staff nurse Sanjit Moore that Hayley had a COUGH and a COLD. Hayley has never had a COUGH and a COLD in her life. (I only found out Sheila Bennett said this the day after Hayley died)

### Wednesday 7.50am 11/11/09:

Hayley died in the room beside the door on Ward 11. She suffered a cardiac arrest, I called for help but no one came as the door was shut because we were in ISOLATION. I had to leave my dying baby on her own to run for help. PICU came but Hayley's line was down. Adrenaline sprayed over my face 4 or 5 times instead of helping her. I had warned everyone that day her line was failing. PICU tried their best but Hayley was not in a safe place and the extra support that was critical to her survival had not been put in place because nobody listened.

Hayley was OVERLOOKED and NEGLECTED and SUFFERED. She didn't receive the appropriate care/treatment she required and deserved. This neglect resulted in her death. The medical team on Ward 11 did not react fast enough or take effective measures that would have saved Hayley. They discarded and dismissed the family pleas that something was seriously wrong.

During the week before Hayley died, my dad Edward Stevenson asked Dr Ben Anderson on three separate occasions "were Hayley's problems life threatening, would she require further surgery to make her better" Dr Ben Anderson was very adamant "No, her condition wasn't life threatening and she wouldn't require any further surgery". Dad kept asking and persisting because Hayley's condition was deteriorating, he also asked two other doctors the same question. They all reassured him Hayley wasn't in DANGER. He asked this question 6 times in total over a 7 day period.

**The staff were shocked that Hayley died. We, her family, were not.**

Dates of neglect: Friday 06/11/09 to Wednesday 11/11/09

Where: Ward 11 in the room closest to the door

I have summarised Hayley's time on Ward 11 to fit the complaints letter format but I respectfully request that you read the LIST OF EVENTS and WHAT HAPPENED AFTER HAYLEY DIED including reference photos.

From Friday 6<sup>th</sup> November to Wednesday 11<sup>th</sup> November my parents; Edward and Sylvia Stevenson and I repeatedly told everyone that we were very worried that Hayley's condition had suddenly deteriorated, especially as she had been doing so well.

**Saturday 31/10/09 to Thursday 05/11/09 - Hayley had made excellent progress**

- Eating solids
- Guzzling down bottle feeds
- Playing peek-a-boo
- Sitting up in her high chair
- Oxygen level down to 0.2 – 0.3 litres of oxygen

Note: Refer to reference photos taken Thursday 05/11/09

**Friday 06/11/09 to Wednesday 11/11/09 - Hayley's health went downhill fast**

- Struggled to breathe – started fighting for every breath
- Head started bobbing – became increasingly pronounced
- Refused bottle feed
- Refused solids, even her favourites; Cheerios
- Lethargic
- Hardly opened her eyes, slept all day and night
- Head box – 5 litres oxygen, nil by mouth, IV drip
- Infection in chest wound looked very aggressive – became worse each day
- Gaining weight – looked puffy like she was retaining fluid

**Monday 09/11/09**

**WARD ROUND:**

Dr Ben Anderson told his colleagues that Hayley was FINE. My Dad stood between Dr Stumper and Dr Anderson and said "excuse me, the child is not FINE"

**MUM SPOKE UP:**

Mum said she was embarrassed asking again and again about Hayley's lungs. Dr Stumper

listened to Hayley's chest and said she was clear. He organised blood gases and x-ray scans. Dr Stumper ordered the tests based on Hayley's grandparents concerns, not Dr Anderson's belief/diagnosis that Hayley was FINE.

### X-RAY

APPROX 11 – 11.30am:

- X-ray showed Hayley's upper right lung was starting to collapse (**MASSIVE CONSOLIDATION**)
- SHO only informed family at 5.30pm about Hayley's results
- SHO informed us – No need for concern, it wasn't serious – **She lied**
- Hayley didn't need physio until the next morning

### Tuesday 10/11/09

1.30am:

- Hayley in severe respiratory distress
- Right lung collapsed – consolidated
- Left lung compromised
- Head box – 5 litres oxygen, nil by mouth, IV drip

#### Special Note:

**SHO Pam Dawson was excellent, she responded quickly and professionally. I am eternally grateful to her.**

### Tuesday morning – 10/11/09

8.00am:

After Hayley's lungs collapsed I told everyone on Ward 11 that Hayley had been overlooked, neglected and was suffering. I kept repeating this to everyone and anyone from physio, staff nurses, SHO, doctors, ward manager, ICU and surgeon.

Approx 9.00am:

Jackie Clinton, Ward Manager asked me if I wanted to make a formal complaint, she was very kind. I thanked her for listening but said I just wanted them to HELP HAYLEY. Hayley needed me; I didn't have time to fill out forms while my baby was lying suffering.

Approx 10.30am:

Told Dr Zdenka Reinhardt Hayley had been neglected and I was seriously worried about her health. She was very kind and apologised. She told me Hayley's infection was number one priority and she was organising extra support for her.

1.00pm:

Hayley put in ISOLATION. Junior Sister Sheila Bennett turned isolation sign around and shut the door. She told staff nurse Sanjit Moore and student nurse Simone that Hayley had a cough and a cold. Hayley has never had a cough and a cold in her life. We were told to avoid common areas in case we spread infection to others. Very scared; felt like prisoners.

### **Wednesday 11/11/09 – HAYLEY WAS IN SERIOUS TROUBLE**

7:00am:

- Hayley's stats had dropped to 88
- Alarm went off for 15 mins but no one came
- Hayley working harder to breathe

7:15am:

- Fetched nurse and told her I was worried about Hayley's breathing
- She turned off milk feed + got SHO
- SHO checked Hayley
- Told me she was fine
- Put Hayley on half IV and half milk

7.30am:

Shouted for help but no one came. Door was shut because we were in ISOLATION. Had to leave Hayley on her own and run for help.

- Hayley's stats suddenly dropped to 65
- Started turning blue and fighting for breath
- Mouth sucked in on the right side, lips puckered out on the left
- Eyes were full of terror, started rolling back in her head
- PICU were called, they bagged Hayley and put a long tube down
- Monitor flashed cardiac arrest
- Line was down, had problems administering adrenaline – it kept spraying over my face. This happened 4 to 5 times
- Tried to resuscitate
- Felt heart come back after 18 minutes then COLLAPSE
- After 20 minutes resuscitation Dr. Adrian told me "sorry mum, we've lost her"

### **7.50am Wednesday 11/11/09 – HAYLEY DIED**

1 YEAR, 1 MONTH AND FIVE DAYS OLD

### **What Did I Do to Try and Resolve this Matter**

11/11/09:

As soon as Hayley died I told Justine Kidd, Cardiac Liaison Sister that I didn't want the hospital to touch Hayley, I wanted someone independent, I didn't trust them. "Hayley was neglected and over-looked when she was alive and suffering, I'll be damned if she'll be neglected and overlooked now that she is dead". "You're not to do anything without my prior knowledge and permission; I have no faith in the hospital".

Dr. Zdenka was kind and wrote that I wasn't happy on the doctor's notes. She came in and showed me the notes before she sent them off to the coroner.

#### **Thursday 12/11/09**

I talked to staff members in Ward 11 the day after Hayley died. I approached everyone I could. I was calm, steady and spoke quietly, I didn't cry, I didn't want to upset the other parents and didn't want to dishonour Hayley's memory by acting inappropriately. I needed everyone finally at last, to take me seriously.

I informed everyone that Hayley had been overlooked and neglected and there was no need for her to die, I kept repeating this. Only one person was honest enough to face the truth, that person started crying and said "I completely accept your criticism, I was so shocked when I heard Hayley died, I completely accept your criticism". I was touched by their honesty but completely devastated. I could see they were sorry, I thanked them for their integrity but made them promise to please listen to the families if they believe something is wrong with their baby. They know their baby better than anyone else.

I asked Dr. Ben Anderson why he didn't listen to the family. We had begged and pleaded that something was seriously wrong. There was no need for Hayley to die. Ben looked me straight in the eye without blinking and informed me that "HAYLEY WAS FINE", I responded "BUT BEN, HAYLEY IS DEAD". Ben said this in front of Cardiac Liaison Sister Justine Kidd and a member from PICU. He did not offer any sympathy; he only said three words; "HAYLEY WAS FINE"

#### **Thursday 12/11/09 – Wednesday 18/11/09**

I told everyone that Hayley had been neglected and didn't need to die. I talked to the coroner and expressed my grave concerns. I rang PALS who referred me to POhWER. I wrote a diary, logged information and put it all in a letter which I hand delivered to Jackie Clinton, Ward Manager on 17<sup>th</sup> November 2009. I faxed the same letter with amendments on it from the coroner's office. Please refer to WHAT HAPPENED AFTER HAYLEY DIED for a more detailed account.

#### **I would like the following points addressed in response to this complaint:**

Please ask four members of the medical team to read my letter and additional attachments including photos.

- Dr William Brawn
- Dr Stumper
- Dr Ben Anderson
- Dr Zdenka Reinhardt

I would like their professional opinion on the following questions. Please answer in writing. I value their medical opinion and believe it is a reasonable request. If they were in my position I'm sure they would want to know what happened to their baby. It would give me great comfort. They can put forward more than one theory if they wish. I would prefer if the doctors were approached individually to allow for a separate point of view.

- What do you think killed Hayley?
- Do you think you missed anything?
- Please explain what you think you missed?
- What would you have done differently if anything? For example: Transfer Hayley to High Dependency or PICU when she was put in the head box on Tuesday morning.
- What tests would you have run or actions would you have taken now that you are aware that Hayley was in serious danger and is now dead? For example: If Hayley was in PICU instead of Ward 11 when she suffered her cardiac arrest, would she still be alive today?
- Rate her chances. For example: PICU – 90% survival rate } Fill in the  
Ward 11 – 20% survival rate } percentage values
- If Hayley was in PICU would she have had a backup line to administer life supporting medication such as adrenaline?
- Hayley's line was not functioning, how did this impact on her survival rate?
- I believe Hayley would still be alive today if the adrenaline was able to be administered straight away. It would have given PICU time to stabilise her. Do you agree or disagree? Please explain
- What extra support or specialised equipment would have been available in PICU? For example, defibrillator/ventilator. How would that have helped Hayley compared to what was done in Ward 11?
- I believe if Hayley was in PICU she would still be alive today. YES or NO? Please explain
- Who made the decision not to send Hayley to PICU and why?

Same questions as above but comparing and contrasting High Dependency with Ward 11; the room next to the door.

*Note: I have abbreviated Room Next to The Door as RNTD and High Dependency as HD*

- If Hayley was in HD instead of RNTD when she suffered her cardiac arrest would she still be alive today?
- Rate her chances: HD - ? survival rate } Fill in the percentage

RNTD - ? survival } rates

- If Hayley was in HD would she have had a backup line to administer life supporting medication such as adrenaline? Would the nurses have been more vigilant about keeping it operational because she was in HD?
- If I told the nurses in HD that I was worried about Hayley's line failing would they have listened?
- What extra support or specialised equipment would have been available in HD? How would that have helped Hayley compared to what was done in RNTD?
- I believe if Hayley was in HD she would still be alive today. YES or NO? Please explain
- Who made the decision not to send Hayley to HD and why?
- I believe Hayley's position on Ward 11 next to the door directly contributed to her neglect and ultimately resulted in her DEATH. Please respond: Agree/Disagree and why?
- I believe that medical team did not take the family's concerns seriously that Hayley was in danger because of her location. Her position on Ward 11 indicated to everyone that senior management had decreed that Hayley was out of danger and on her way home. She was sharing a room with a baby who was off all their monitors and whose only concern was establishing feeds
- A member of PICU saw me on Ward 11, he gave me a huge thumbs up and a smile and said "close to the door, you're on your way HOME" So when Hayley started failing fast no one believed us or did anything about it until she ended up in a head box. I would like the doctors' comments. Is that a fair assessment? YES or NO? Please explain criteria for positioning on the WARD
- Dr Zdenka Reinhardt told me on Tuesday 10/11/09 at approximately 11.30 to 12pm she was organising extra support for Hayley, what was that? Did it happen? Why not?
- Whenever mum and dad went to get the results of Hayley's x-ray and gases on Monday 09/11/09 the SHO was busy looking after her high priority patients. I understand that it is necessary to look after high risk patients first but Hayley was the one in DANGER. Unfortunately she was next to the door and the last to be seen, even though she was the most vulnerable. That is why my parents and I were so devastated that nobody took our concerns seriously.
- Hayley was overlooked. Do you AGREE or DISAGREE? Please explain?
- When Hayley was discharged from PICU I was informed that she would go straight to HD. In Ward 12 Hayley was put next door to HD in the open ward but it was right beside the nurses' station. Two days later Hayley transferred to Ward 11, I asked if she could stay. They promised me she would be in High Dependency and would be better off in Ward 11. Hayley was put in the room next to the door; she couldn't get any further away from the nurses' station. I was gutted, why was I lied to twice?
- Who made the ultimate decision and why?
- Hayley had puncture wounds on both her legs, just below the knee. I noticed these when I was bathing and dressing her. I distinctly remember a stabbing motion was used to put the implement in. What was this? What were the PICU team trying to

administer? Was it adrenaline? Did the PICU team manage to administer any adrenaline with this implement?

- Hayley had a line in her groin; did the PICU team manage to administer any adrenaline into the Arterial Line?
- How long do you have until the patient is at the point of no return? How many minutes/seconds?
- Every time Dr. Rich asked for adrenaline I kept getting sprayed in the face, approximately 4 to 5 times – was this spray Liquid Adrenaline?
- Did the line come out when the bandage was being unwrapped? I heard someone say “is that her line out?”

PICU did their best, the ward failed to make her safe. I had told the staff nurse that night that Hayley’s line had been occluding 4 to 5 times an hour. I said Hayley’s lines were always failing and she had to have a Brovine line in (I don’t know correct medical term) when she was in Belfast. \* It could easily take an hour and a half to put her line in. Most of the time they had to call for someone more senior and experienced. The staff nurse didn't take me seriously. We were next to the door.

X-Ray – Hayley’s x-ray at 11.30am on Monday 09/11/09 showed that her upper right lung was starting to collapse.

- Who knew about the results?
- Why was nothing done about it?
- The SHO informed us that “it was of no concern – nothing serious”, who made that decision?
- Why was Physio not organised until the following morning?
- If Hayley had physio sooner could that have prevented her severe respiratory distress at 1.30am on Tuesday 10/11/09?
- There was no need for Hayley to suffer – YES/NO? Please comment
- Did the long tube incident in PICU that accidentally collapsed her lung contribute towards her death?
- Why did PICU call Hayley’s death at 20 minutes, why didn’t they work for longer?
- What is the average time for resuscitation?
- Why did PICU not use a defibrillator?
- How serious was Hayley’s wound infection in her chest?
- Did Hayley still have a staph infection or had it developed into something more serious?
- Could the infection have killed her?
- My dad was very upset that Hayley’s dressing was not getting changed often enough. It was constantly filling up with pus. Did this make the infection worse?
- Hayley was given a new antibiotic at 8.00pm on Tuesday 10/11/09 to prevent a lung infection. Would that have had any connection to her death?
- Hayley had become very puffy and looked like she was retaining fluid, what does that indicate? Was it a sign of heart failure?
- What was the result of Hayley’s MPA swab taken at 6.30 – 7.30pm on Tuesday 10/11/09?



- Ben told my parents on Ward 11 that Hayley had done well to recover from her pneumonia. My parents and I were horrified, nobody at PICU had mentioned anything about pneumonia
- Why did nobody tell us?
- How serious was it?
- What treatment did she receive?
- How long did she have it?
- How many children die during surgery
- How many children die 24-48 hours after surgery
- How many children die 2 weeks after surgery
- How many children die 28 days after their heart surgery?
- How many children die in the room next to the door on the ward?
- If I had made an official complaint on Tuesday morning 10/11/2009 when Jackie Clinton asked me - what would have happened? Would they have moved Hayley then to PICU? Would they have moved her if I had screamed and been obnoxious?

I put my faith and trust in you to take care of my only child; you held all my hopes and dreams in your hands. I was completely devoted to Hayley, she was my whole world. Why did nobody help save Hayley? Why did nobody listen to me, her mummy? Why did nobody listen to her grandparents? We have no medical training but we knew Hayley was in DANGER. My mum kept asking everyone "what about her lungs" and my dad asked on six different occasions "was Hayley's condition life threatening". I refused to sleep for 38 hours and told everyone she had been neglected.

My poor husband Bobby is tortured. He sacrificed so much time with Hayley to give her the best start in life. He missed his own father's funeral to be with his baby girl when she was getting her shunt. He flew back and forth from Australia 18 times in 18 months to be with his best girl. We never got to be a proper family. He kept himself busy with renovation jobs around the house to make it perfect for Hayley. He hated being on his own but was comforted that Hayley was in SAFE HANDS.

It was my choice to go to Birmingham; I was so excited Hayley was getting the BEST. We could have chosen Dublin or Brisbane but I wasn't interested.

Bobby deserves an explanation. When he arrived on Friday 13<sup>th</sup> November all I had to offer him was the baby grow Hayley had died in and a lock of her hair. He was shattered.

On Thursday 5<sup>th</sup> November she had been sitting up eating toast and Cheerios and playing peek-a-boo with her bib, on 0.2 of oxygen. The following Wednesday she was DEAD.

Ask each doctor to explain to Bobby what went wrong and to put forward a personal comment. I will not accept Hayley was FINE.

I've watched my family disintegrate in front of my eyes; we can hardly bear to look at each other. It's horrible to watch the ones you love in so much pain. I can't even look at myself in

the mirror without flinching.

I watched the light and life fade from my baby girl but now I have to watch the life and light drain from my family. Hayley is dead but my family are dying. We are the living dead. My poor mother is traumatised by the whole Birmingham experience, it's sad enough Hayley is gone and never coming back but the way Hayley died is torturous to live with.

We come from a small Irish town where everyone knows everyone's business. People can't cope with what happened to Hayley. I haven't really left the house, I hide away but poor mum has to do her grocery shopping. People either cross the street to avoid her or crumble in front of her eyes. She comes home from town screeching. My mum was a fun-loving person and loved to laugh, everyone gravitated towards her, she always made them feel special. Now they avoid her like the plague or add to her suffering by trying to comfort her. I love my mum with all my heart, she is a wonderful woman but now she is just an empty shell.

Christmas was her favourite time of the year, Hayley made it even more special, now I watch her ripping up Christmas cards and putting them in the bin. My mum is the busiest person I know, running around helping people, now all she says is "half a day is long enough" and disappears to bed, she doesn't even say goodnight. Sleep is her only escape but then every time she wakes up she has to relive it all over again.

Spare a thought for her at Christmas, she watched her granddaughter die like an abandoned animal surrounded by experts who were too arrogant to listen to a pathetic old granny. It took great courage for my mum to speak up about Hayley "I am embarrassed asking about her lungs - what about her lungs?"

Dr Stumper; you listened to Hayley's chest on Monday morning and told mum they were clear. The x-ray at 11.30am showed that the right lung was starting to collapse. \* **Medical notes confirm MASSIVE CONSOLIDATION left lung. VOLUME loss right lung.** I saw it. We were told by SHO that "it wasn't serious -no need for concern". I watched my daughter's two lungs collapse Tuesday morning at 1.30am. I saw the x-ray

The pathetic old granny knew more than you. Tuesday morning when you came in to see Hayley, mum jumped up like a child looking for attention and asked "what about her lungs - what about her lungs?" You looked incredulous and agitated that she dare ask. You shouted out "Physio" and looked around you "will that make her better?" mum asked, "Yes", then shouted "Physio" again and charged out of the room. Three pathetic words; was that the best you could do for a petrified Granny?

Dr Stumper I have contempt for you.

Does it make you feel big to belittle people?

You are in a position of power, you make life and death decisions.

My baby is dead and my Mum is destroyed.

Would it have inconvenienced you so much to make an effort to be more humane?

My poor mum keeps saying "the look of contempt on Dr Stumper's face will haunt me till the day I die".

Does your heart still swell with pride now?  
I watched my baby's heart collapse.

Dear Dr Zdenka; you were very kind. I know Hayley's death has affected you and has made a difference. I wish I had talked to you sooner. Thank you for trying.

Dear Dr Brawn - You gave us a future, it was beautiful for a while.

Dr Ben Anderson:

I believe there is no hope for Ben  
He is a lost cause.

The next time a grieving mother comes to you and asks 'what has happened to my baby, why didn't you listen?' say "I am so sorry for your loss, please accept my sincere condolences". Do your best to pretend you have pity in your eyes instead of defiance.

General questions to be investigated by the Complaints Panel:

- Why was there no ward round on Tuesday 10/11/09? Hayley needed to be seen by as many people as possible
- Was it because I had been telling everyone that morning that Hayley had been neglected?
- I feel that I was denied the right to tell the rest of the medical team that Hayley was in terrible trouble. Maybe one of them would have taken me seriously and could have saved Hayley
- Please investigate why Junior Sister Sheila Bennett told Sanjit Moore that Hayley had a cough and a cold. Why did she lie? Why did she feel compelled to put us in ISOLATION for no medical reason?
- I want Shelia Bennett to read my complaint letter and attachments and recognise and acknowledge the anguish and distress she caused.

Her deliberate "act of malice" seriously damaged Hayley's chances of medical support. We were scared to leave the room to get help with Hayley's line. We would spend 10 minutes trying to fix it ourselves then another 5 minutes worrying about leaving the room to get help. It would occlude 4 to 5 times an hour. The whole time we were getting stressed Hayley wasn't receiving her proper amount of fluids. We took it in turns leaving the room to ask for help. This went on all day.

When Hayley suffered her cardiac arrest no one heard me cry out because the door was SHUT because we were in ISOLATION. I had to leave my dying baby alone to get help. I am haunted every night by the look of terror in her eyes as I ran off. When they called PICU my first thought was Hayley needs help now, it's going to take too long for them to put on the plastic aprons for ISOLATION. Hayley's struggling to breathe; we're running out of time, there is no time to spare. I FELT SICK TO MY VERY CORE.

Shelia Bennett's vindictive act caused so much suffering.

I was meant to bump into staff nurse Sanjit Moore the day after Hayley died. I don't know why I asked for the reason Hayley was put in ISOLATION. I was devastated when Sanjit told me "Hayley had a COUGH and a COLD".

I want a full investigation. I want to know what action will be taken, who will Shelia Bennett be reviewed to, how does the Trust deal with situations like this. I believe there is a civil liberty rights issue that needs to be addressed.

Is it medical malpractice if you lie about a patient's condition which seriously affects their direct access to medical treatment which can save their life?

Hayley died in ISOLATION.

I want this matter to be treated seriously and investigated fully.

- How can you prevent this happening again?
- Did Hayley's monitor have a specific alarm/warning that indicated she was in cardiac arrest? I saw a monitor that flashed cardiac arrest but I wasn't sure if it was Ward 11 or PICUs
- Why did Alison Stanton not wait for me to forward my Official Complaint Letter?

I rang her on Friday 27<sup>th</sup> November to tell her I was writing up an official complaint letter but it was taking me a while as I was scared of making a mistake and found it a very painful experience. She forwarded the letter dated 17<sup>th</sup> November without my permission or knowledge. The basis of my complaint letter was solely focused on the fact that nobody LISTENED. I was horrified when I discovered what she had done. It's like rubbing salt in an already gaping wound. Who is Alison Stanton accountable to? I kindly request that all phone calls be recorded and kept on file.

I feel a terrible pressure to hurry my Official Complaint Letter now and reserve the right to ask relevant questions in the future as I am remembering more every day.

- Why did Justine Kidd, Cardiac Liaison Sister stand back and say nothing when Dr. Ben Anderson said "Hayley was FINE? He did not offer sympathy, only denial. This was a verbal attack on a grieving mother. Please ask Justine if she found this behaviour acceptable, I want her personal comment.
- Please inform the sister who took Hayley's hand and footprints that I was upset by her attitude. She brought me blue, orange and purple ink. I had to tell her "Hayley was a little girl, where was the PINK". She said she couldn't find any. I told her to look again, she informed me that it would take a long time; I told her "I didn't care". She came back in an hour and a half with a pink ink pad smudged with purple. **IS THAT THE BEST THE HOSPITAL CAN DO?** This is pretty basic stuff here; I shouldn't have to bring this up in a complaint letter. **I FOUND IT DEMEANING TO HAVE TO ASK FOR PINK INK FOR MY DEAD BABY GIRL.** Please address this issue.

As a result of this complaint, I would now like the following:

- Answers to all of my questions
- Full explanation of what happened to Hayley
- Full investigation into Junior Sister Shelia Bennett's behaviour, what arrangements does the practice have in place to deal with "deliberate acts of malice" which result in anguish and suffering? What action will be taken?
- What changes will be made so the same thing will not happen to anyone else?
- What practices/procedures will be implemented to prevent the needless loss of a baby?

There needs to be a shifting awareness of more responsibility. I hate the cliché 'lessons to be learnt'. There needs to be valuable learning. I believe 'EGO' and complacency killed Hayley. The doctors knew best after all, they are medically trained, we are not. But we knew Hayley best and now she's DEAD because they dismissed us.

I saw my wonderful obstetrician today, I told her what happened to Hayley, she held my hand and wept for me. I had a complicated pregnancy and she helped save my Hayley, she took care of us both and I love her with all of my heart. I got to recognise the sound of her footsteps on the ward; she made me feel safe and took care of my baby girl. I watched her face grimace when I said nobody listened. She told me "FIRST RULE OF PAEDIATRICIANS WAS ALWAYS LISTEN TO MUM". I just shuddered when she told me that

I absolutely adored my little girl and would give up my life in a flash to have her back.

I'm breaking my back trying not to hate and to forgive. I'm scared of having a face etched in pain and bitterness where strangers will look and say to themselves she's had a hard life.

I promised Hayley I would have a beautiful life to honour her memory but when I hear things like that it tortures me.

PLEASE GOD WHY THE HELL DID NOBODY LISTEN?  
WHY DID MY BABY HAVE TO DIE?

I look forward to receiving your acknowledgement of this letter. I would like you to carry out a full investigation into my concerns and provide a response in accordance with the NHS Complaints Procedure as soon as possible.

Because of the very serious nature of this complaint which resulted in the death of my only child, I respectfully request that my complaint be dealt with **URGENTLY.**

I am driven by a 'duty of care' and responsibility to my friends from the Clarke Clinic who have been referred to Birmingham Children's Hospital. I am terrified the same thing will happen to them, I could never live with myself if they were overlooked and neglected in the same way as Hayley, especially when one of the medical team has already accepted blame. When I told them Hayley had been overlooked and neglected and there was no need for her to die they replied "I completely accept your criticism". They said this TWICE

I am 38½ years old and my only child is dead.

It is the saddest thing in the world to lose your baby.  
It's a terrible burden to live with the guilt that she suffered and was neglected.  
But it's a living hell knowing that not enough was done to save my 'wee' Hayley.

Please do not hesitate to contact me if you need further information.

Yours sincerely

PAULA STEVENSON

TO: Patient Relations Manager [alison.stanton@bch.nhs.uk](mailto:alison.stanton@bch.nhs.uk)

CC: Coroner [jon.d.hoskin@birmingham.gov.uk](mailto:jon.d.hoskin@birmingham.gov.uk)  
POhWER [sarah.smith@POhWERicas.net](mailto:sarah.smith@POhWERicas.net)  
Dr. William Brawn [laura.preston@bch.nhs.uk](mailto:laura.preston@bch.nhs.uk)

## LIST OF EVENTS

**RE: NHS COMPLAINT  
HAYLEY ELIZABETH FULLERTON  
06/10/08 – 11/11/09**

**Hayley Elizabeth Fullerton, 06/10/08 – 11/11/09**

I would like to take this opportunity to officially document my grave concerns about the treatment of my only child Hayley Fullerton on Ward 11 at Birmingham Children's Hospital. I was especially concerned about her treatment between Friday 6<sup>th</sup> November 09 and Wednesday 11<sup>th</sup> November 09.

The last four days leading up to Hayley's death, my parents and I begged and pleaded that she was very poorly and that something was seriously wrong. At the end I watched my daughter struggle and fight for every breath that she took. Her head bobbed more each day; it was very painful to watch. Dr Ben Anderson, Registrar repeatedly advised us during that time that there was no need for concern, Hayley was FINE. I talked to Ben the day after she died, I told him how tragic it was that action was not taken sooner and he looked me straight in the eye and said "*HAYLEY WAS FINE*", "*But Ben, Hayley's DEAD*", I replied.

**Special Note:** 24 hours before Hayley died I told every staff member on Ward 11 that Hayley had been over-looked, neglected and was suffering. She was suffering because no-one had helped her, I told them I had lost all faith and trust in them. I didn't sleep for 38

hours and refused to leave her side. The staff kept telling me to get some rest; I told them *"how can I rest when Hayley is in such a terrible state?"*

Jackie Clinton, the ward manager asked me on the morning of Tuesday 10/11/09 if I wanted to make a complaint, I told her all I wanted was for someone to help my baby. Hayley had been ignored long enough, I wasn't interested in filling out complaint forms while she lay there struggling to breathe. I thanked Jackie for her help and said how relieved I was that at last, someone was listening. All I wanted was Hayley to get the help she needed and deserved.

## **22 HOURS LATER, HAYLEY WAS DEAD**

During the week before Hayley died my dad asked Dr. Ben Anderson on three separate occasions "Were Hayley's problems life threatening? Would she require any further surgery to make her better?" Dr. Ben Anderson was very adamant and said "No, her condition wasn't life threatening and she wouldn't require any further surgery". Ben was astounded that my dad would ask such a thing.

My dad is very calm and collected and doesn't stress or interfere so this was a huge deal for him to ask such a question but he was worried, he asked the other doctors another 3 times before the week was out. Everyone humoured him and said she was fine.

Please recognise the fact that this is the most difficult but important letter that I have ever written. I respectfully ask for 15 minutes of your time to listen to Hayley's story.

### **12/10/09**

Hayley was admitted to Birmingham Children's Hospital for corrective heart surgery.

### **14/10/09**

Dr William Brawn performed corrective surgery on Hayley. He did an amazing job.

### **14/10/09 to 31/11/09**

Hayley had an extended stay in PICU because of two failed attempts to take her off the ventilator.

There was a problem when they accidentally collapsed Hayley's right lung with the long tube, it was one millimetre too long. \* **Medical notes confirm it was 5ml too long.** It wasn't picked up in the first x-ray but was only discovered 5 hours later. I did not include this information in my original letter to ward manager Jackie Clinton for 3 reasons:

- It was a genuine MISTAKE. The PICU staff did their best to rectify the problem, they were very diligent and I have a lot of respect for them



- My original letter was focused on Ward 11. Hayley had been overlooked and neglected which resulted in her death
- I was worried that the long tube mistake was not included in Hayley's medical notes and no-one would believe me

I am documenting it now as it is an important part of her medical history. I did bring up the long tube incident with the Cardiac Liaison Sister, Justine Kidd. She offered to make further enquiries on my behalf, I told her I was upset but believed it was a genuine mistake and didn't want to make trouble for anyone so I let it go. I told Dr Adrian that I wasn't happy about the long tube collapsing Hayley's lung. I brought it up when they were talking about taking the long tube out for the third time, I told him I wanted the most senior and experienced member of the team. Hayley had been through enough and I wanted it done right, not in the middle of the night and I had to be there. Adrian said "point taken" and he took care of it. I also mentioned the long tube incident to the Clarke Clinic when they rang up intensive care to ask me why Hayley was in for so long and I told Ward 11 staff.

### **C-Pac**

PICU put Hayley on C-Pac and kept a careful eye on her lungs. She hated the mask and kept pulling her hair out. I started staying in PICU at night time to pacify her as best I could. She wasn't sleeping and spent all night trying to rip her mask off, it was horrible but she got through it. I was very proud of my little girl

### **31/10/09**

Hayley was getting discharged from PICU. My family were very excited and I was bursting with joy. My Australian husband Bobby and I were looking forward to finally taking Hayley to Australia to finally be a family.

Dr William Brawn came to see us, he asked me if Hayley had any respiratory problems before, I told him no. He asked if she had any chest infections, I told him no. I told him when she was discharged from hospital in Belfast at 9½ weeks old that I didn't really leave the house for 3 months in case I got the cold and gave it to her. I only went to doctor appointments. I also said that when Hayley had her BT shunt she was in and out of intensive care in 23 hours, she didn't need physio and she had no post operative complications.

I suddenly had a feeling Dr Brawn didn't know about the long tube incident and it wasn't in the notes. I had grown really fond of everyone in PICU and was really happy to be discharged and because Hayley had done so well, I didn't see the point in pointing the finger

of blame or landing someone in it. I truly believed we were out of the woods. I know it sound silly but I felt protective of the PICU team.

I told Dr Brawn that Hayley was a little bit congested before her operation but she didn't have a temperature or cold. I didn't say anything about the long tube. I feel stupid now that I didn't mention the long tube.

### **31/10/09**

A nurse came to transfer us to Ward 12, she told me we were going into High Dependency. Hayley had her dressing changed before we left as it was a little bit yellow and sticky. When we arrived in Ward 12 they put us in the open ward, they said we were next door to High Dependency but Hayley was closest to the nurses' station. I was worried but Hayley loved the open ward and was so excited to be in with the bigger kids so I didn't say anything.

### **01/11/09**

A nurse told me we had to move to Ward 11, I told her Hayley loved it in Ward 12 and can we please stay as she'd been pulling her hair out in intensive care. I told her we were supposed to be in High Dependency but then we weren't and now you're moving us just when Hayley's settled. They let us stay, I was so grateful.

### **02/11/09**

Ward 12 told my mum they had to move Hayley to Ward 11. Mum rang me straight away, I was supposed to be sleeping. I rang Ward 12 and told them Hayley loved Ward 12 and could we please stay, I even cried which is completely out of character for me. I asked to speak to the manager and waited for her to ring. I gave in after an hour and a half and told my dad to tell the nurses I didn't mean to cause trouble and we would move. The manager rang me to thank me and told me it was better in Ward 11 because Hayley would be in High Dependency, I didn't feel so bad that I had caved in. The Irish Cardiac Liaison nurse also told my mum that Hayley was being put in High Dependency.

When I came in at 6.30pm to do the night shift I was horrified when Hayley was dumped at the door, the furthest away from the nurses' station. Her neighbour was a baby who was off all their monitors and was just establishing feeding before they sent baby home. This was the complete opposite of HIGH DEPENDENCY. I was worried that Ward 11 thought I was being difficult because I asked to stay in Ward 12. I felt really guilty and thought my baby

was being punished because I spoke out, so I said NOTHING.

I was trying to get back into doing days and sleeping in the ward at night but because Hayley wasn't in High Dependency or even close to the nurses' station we all agreed as a family, that I would do nights and mum and dad would do days, we even flew her 19 year old cousin Kirsty over for 5 days to play with Hayley. Kirsty had already been over for 4 days when Hayley was in PICU.

Nobody seemed to take much notice of Hayley's monitor when it alarmed, it was a common occurrence for it to go off for 15 to 20 minutes and nobody would come.

### **02/11/09**

I was worried Hayley wasn't getting enough attention, I even bribed one of the nurses in the hope that she would tell the other staff and it would encourage them to show more care towards my baby. I gave staff nurse Emma Wright a £100 voucher for Monsoon. She helped me see the dietician and I wrote in the card "Thank you for listening and helping Hayley". I prayed she would show it to the other staff.

Hayley loved seeing her cousin again and she really thrived the next few days. There were four of us now looking after Hayley and she loved the attention. Hayley started back on bottle feeds and solids, she was sitting up in her high chair eating toast and Cheerios and beef stew. She was gaining weight and had gone down to 0.3/0.2 litres of oxygen. She started playing peek-a-boo with her bib. Hayley had been miserable in ICU so it was beautiful when she started reading her books, playing with her toys and happily babbling away.

**Note:** Please refer to photos taken Thursday 5<sup>th</sup> November 09 of Hayley playing peek-a-boo, eating toast and sitting in her high chair.

### **RAPID DETERIORATION**

Previously Hayley had a staph infection in her chest incision, she had been on oral antibiotics for 11+ days but it really wasn't healing, in fact it was getting worse. The infected area was pus filled and had to be cut open by the surgical team.

### **06/11/09**

Hayley was started on a concentrated course of IV antibiotics to help clear up the infection. Her oxygen was turned up to 0.75 litres because we were told her body would be working harder to cope with fighting the infection. We immediately noticed a huge difference, Hayley went off her food, refused her bottle and became really listless, all she did was sleep and she was working really hard to breathe. I asked if she was having a reaction to the antibiotic and was told that she was just focusing on fighting the infection. Her head started bobbing. Dr Ben Anderson told me she was working harder to fight the infection and it took a bit more

time for little babies. I believed him.

## 07/11/09

Hayley became worse, she slept all day and all night, she looked in distress when she breathed and her head started to bob more. Mum and dad told the medical team that they were worried about her, they told mum and dad the medical term for “head bobbing” and said they had already put it in her notes. \* **They lied. Hayley's head bobbing was not mentioned in the notes.** I was agitated when I heard this because the Clarke Clinic in Belfast had trained us to be very aware of any changes in Hayley’s breathing. We had a satellite link set up in the house that connected directly to the hospital. They checked her breathing and general condition every week. We had never seen Hayley breathe like that before so it was very distressing.

Ward 11 advised mum and dad that Hayley was just catching up on her sleep. Mum saw Dr Ben Anderson, she told him that Hayley was “*very poorly*”; he asked her what she meant and mum told him that Hayley was a very sick little girl and she was worried about her head bobbing and her lungs. Dr Ben Anderson said that he had seen worse and that she had done really well to get off the C-Pac so quickly and recover from pneumonia. Mum was shocked when pneumonia was mentioned. “*Pneumonia, I never heard tell of Hayley having pneumonia!*” He gave a brief description of what pneumonia was then told mum that “*Hayley is FINE*”.

Later on, a stranger who was visiting a patient walked past Hayley that day, they stopped and watched her for a short while then turned to mum and told her “*your child is struggling for every breath she takes*”. Mum was very upset. This stranger had no medical training but he could see that Hayley was in trouble.

There was a problem with Hayley’s monitor. The clinical support personnel complained to her colleague that the new monitors donated by Midland Bank were not as good as the old ones, they weren’t as accurate and kept alarming. She turned the monitor off and said she was going to try and find an old one and asked mum if she was alright looking after Hayley. She couldn’t find an old one but didn’t turn the new one back on, she said that Hayley didn’t really need to be on the monitor as she was on 2 hourly obs. When dad told me that Hayley was on 2 hourly obs I was very worried, I really thought that Hayley needed a staff nurse to take care of her and not clinical support personnel. **Mum and Dad asked all day to get Hayley weighed. They promised they would but didn't bother. Mum was worried because Hayley was looking puffy and felt heavy.**

## 8.00 – 8.30 Change Over

Another support personnel came at change over. I asked her to turn the monitor on all night because I was really worried about Hayley’s lungs, I told her about Hayley’s lung collapsing in PICU and how she was still vulnerable. She checked Hayley and said **she was fine.** \* **Are support personnel qualified to make a medical diagnosis?** I was really confused, The Clarke Clinic had always trained us to look out for even the slightest change in Hayley’s

breathing, they would regularly ask me *“Mum, how is Hayley’s breathing”* because I knew her best and was with her all the time, if there was something wrong I would notice. It was painful to watch Hayley’s head bobbing and fight for every breath she took.

### **09/11/09 Ward Round**

Dr Anderson told his colleagues during ward round that Hayley was FINE, dad said *“excuse me, but the child is not fine”* and stood up between Dr Stumper and Dr Anderson. My dad is very calm and laid back and doesn’t interfere in other people’s business never mind interrupting a ward round but he was just so worried. Dr Stumper listened and organised an x-ray and gases to be taken. Mum said she was embarrassed asking all the time *“but what about Hayley’s lungs?”* Dr Stumper listened to her chest and said she was clear. He asked what happened to the vein in her neck which had been damaged in Belfast. He asked who her doctor was in Belfast and said he would look into talking to her doctor to see if they could provide the same care for Hayley over there.

Mum had asked Justine Kidd on Wednesday about transferring Hayley to Belfast but that was when she was sitting up eating toast in her high chair. She saw Justine later and told her what Dr Stumper said, Justine said that she had asked on mum’s behalf but only when Hayley was ready; she made it clear that the family weren’t pushing. Justine was always very considerate and kind and mum appreciated her asking but was also shocked that Dr Stumper had even brought up Belfast when Hayley was in such a poorly state. Mum told Justine that she had said to dad just that morning that they would be in hospital until Easter because Hayley was so sick.

### **11.00 – 11.30am:**

The x-ray was taken between 11.00am and 11.30am. Mum and dad waited and waited for someone to come and tell them the results. No-one came.

### **Approx 12 – 1pm**

Hayley finally weighed, according to medical notes she was supposed to be weighed every other day. Hayley was weighed TWICE in nine days.

Hayley was 6.31kg

She was previously 6.18kg on the 06/11/09.

Weight gain – 130g.

The staff nurse and student nurse Simone were happy with Hayley's weight gain. My mum was very worried, “I am not happy with her weight. Is it fluid? How can she put on that much weight if she hasn't been eating?” Hayley had hardly eaten any solids since her operation. 26 Days ago. She ate breakfast, lunch and dinner at home. I made all her food from scratch

and added lots of extra butter and cheese. The dietician from Belfast helped me increase her calories. It was very hard to increase Hayley's weight, she averaged 60g a week. The staff nurse told mum she was on the NG feeds, Mum was still unhappy.

#### Approx 5.30pm:

Mum went to the nurses' station and asked if Hayley's results were back, the staff nurse asked the SHO about the results, the SHO outstretched their arm and put their hand up like they were stopping traffic, they said they were busy and they had to do something else first. One of the other staff members rolled their eyes. Mum said she would wait. Mum was worried about Hayley, no-one had come to see her and then she gets treated dismissively. The SHO stood at the doorway but didn't bother coming in. They said Hayley had a collapse in her upper right lung. They weren't overly worried and there was NO NEED FOR CONCERN, Hayley's gases were fine and they would organise physio but didn't say when, then just kept walking. \* Medical notes confirm Hayley had MASSIVE CONSOLIDATION left lung, volume loss right lung. The SHO lied.

I came in at 6.30pm when Dad told me about Hayley's lung, I was really worried and very annoyed that it took so long for us to find out about Hayley's lung. They should know she had problems in ICU; they couldn't even be bothered to come into the room to tell us. I wanted to know if Hayley was getting physio straight away, dad didn't know so he went off to ask and was told it would do until the morning. I was furious but said nothing. I wish I had.

My dad was getting really agitated due to Hayley's wound care or lack of it, he was worried Hayley's dressing was not getting changed enough as it had become quite nasty looking and had to be opened up by the surgical team a second time. Dad was constantly asking for it to be changed but it would only be changed once a day even though it really needed changed twice a day. It didn't take long to fill up with pus and was infected in the lower half. The top half was clean but when the dressing was on too long the pus would travel up to the top half of the wound and get trapped. Dad had been trying to get the dressing changed all day, he had eventually asked for there to be a special inclusion in Hayley's notes for the dressing to be changed twice a day.

Hayley had slept all day, hardly opened her eyes, refused her bottle and just lay there struggling to breathe. She started taking lots of water from her sippy cup, she would guzzle 30-40ml in one go which was unusual for her

#### **8.00 – 8.30 Change over**

Staff Nurse Hayley Stretton was a breath of fresh air; she gave little Hayley excellent care. She changed the dressing when I asked; she was very understanding when I explained how worried I was about Hayley breathing. She checked her out at the start of the night and regularly checked her status. I was so relieved.

10/11/09

At 1.30am I gave Hayley her gravity feed because she was too exhausted to take the bottle but she did guzzle 30ml of water from her sippy cup. I gave her the gravity feed myself as I liked sitting her on my lap and doing it slowly. When I put her back in the bed she vomited, I cleaned her up and washed her down. I noticed her breathing was noticeably worse and called the staff nurse Hayley who fetched SHO Pam Dawson who acted very quickly. Pam was terrific, she organised an x-ray and rang PICU. The x-ray personnel wanted Hayley to come down to the x-ray department, she told them in no uncertain terms that she had a baby in severe respiratory distress and to get up to Ward 11 immediately.

The first x-ray failed and they had to take another one. Pam put Hayley in a head box with 5 litres of oxygen, set up IV fluids and instructed Nil by Mouth. Staff Nurse Hayley was great too; she kept an eye on my wee Hayley when Pam asked if I wanted to take a look at the x-ray. I was very grateful. Pam kindly showed me the x-ray which had been taken earlier in the day and then the most recent x-ray, I was very shocked as I could see a big difference. I could see the upper right lung slightly collapsed in the first x-ray but the second x-ray showed her right lung was very consolidated, (she told me in layman's terms that it was full of gunk) there was hardly any black area which she explained represented area for Hayley to get her breath but most worryingly of all, Hayley's left lung was compromised. All I could think was this was hideous; this could have been so easily avoided.

Pam told me that PICU said she would need a hell of a lot of physio, I asked Pam to get PICU ready for Hayley, she said she would need to speak to her senior but not to worry, PICU was always ready. Pam rang physio at approximately 2.30am to get Hayley help straightaway but I didn't see physio until 8.30am. Pam tried her best.

It was so pitiful to see my poor wee pet in the head box with 5 litres of oxygen. What the hell was going on! Mum, dad and I had been warning everyone something was wrong, we had predicted this but predict is too airy fairy a term because all the warning signs were there, it was obvious. I stroked Hayley's head and tried to comfort her, I couldn't stroke her head for long because I had to shut the porthole in her head box to keep her oxygen levels up. I missed my little girl, all she did was sleep, she was so weak, I hadn't seen her big blue eyes in ages. I told her I loved her and was really sorry everyone had let her down including me. I felt so guilty.

Right, I need a new 'Plan of Action'. I had to shake everyone up for Hayley's sake. I was taught to be polite and respectful but that didn't work, then I tried begging, pleading, being overly nice and bribery. Why wouldn't they listen? This is so serious, my only child is in terrible trouble and I feel so useless. They knew Hayley had lung problems, why didn't they organise physio straight away? It's bad enough they didn't listen to me but to ignore medical evidence. Hayley was in danger and we needed to get out of Ward 11. I will tell everyone I see tomorrow that Hayley has been neglected.

I am quite a proud person and don't like admitting weaknesses. I have lots of friends and I take good care of them, I never ask for help. I always get things done and am a great problem solver but nothing I tried was working. My poor baby was falling to pieces in front of me. I was DESTROYED. I felt useless and pathetic. At one stage I planned to get a knife

and scratch HELP HAYLEY across my face. What did I have to lose? My looks, my dignity; nothing mattered but Hayley.

I know this sounds pathetic but I want everyone who reads this to know how desperate I was. I talked myself out of it because I didn't want to embarrass my mum and dad and I was concerned they would take me away from Hayley as they would have thought I was mentally disturbed instead of a calculated action to exact an extreme response. But writing this now, knowing that Hayley was going to die, I would have done anything to get her HELP. I feel like a coward now.

**PLEASE KEEP READING, I KNOW THIS IS LONG AND PEOPLE'S LIVES ARE VERY BUSY BUT HAYLEY DIES 11½ HOURS LATER.**

**10/11/09**

**8.00am:**

In response to my telling mum about Hayley's lungs, she text:

*"I have been asking and asking about her lungs; doctors, nurses, everyone. Not surprised".*

**8.30am:**

Physio arrived, I told her I was so glad to see her and that I was out of my mind with worry and said *"thank God you're here"*

I started swearing and saying that no-one cared, they watched Hayley deteriorate from Friday but no-one took a blind bit of notice. My poor mum kept asking *"what about her lungs"* and they told us she was FINE. Look at the state of her! She said she was shocked to hear me swear and I apologised if I had offended her, I just felt so desperate and panic stricken. **I said Hayley would be back on the C-Pac pulling her hair out again but at least we'll be back in PICU but when she checked her notes there was no mention of us being admitted to PICU.**

Hayley had her session with physio and was a lot more comfortable, she was a lot brighter and it helped ease her breathing. Physio organised to come back at 1.30pm.

**9.00am:**

I told the new staff nurse Sanjit Moore, just after handover that my little girl had been neglected and that she wasn't getting proper care. Sanjit was wonderful and went straight to Ward Manager, Jackie Clinton who very kindly asked if I wanted to make a formal complaint. I thanked her for listening but said all I wanted was for Hayley to get better, I didn't want to waste my time making a formal complaint because I would rather be putting all my energy



into Hayley as she needed my help. Sanjit was wonderful and made every effort to attend to all of Hayley's needs that day; she actually went above and beyond. I will always be grateful to her. **Medical notes do not mention anything I said. I wish I had made a written complaint. I made the wrong decision and it will haunt me forever.**

11-12pm

I saw Registrar Zdenka Reinhardt and told her that Hayley was in a terrible state and I believed she had been neglected. Zdenka was very kind and actually apologised, she told me that Hayley's wound infection was the number one priority and she would organise extra support for Hayley. **I was so relieved; I thought extra support would mean we would get moved to PICU at last or at the very least High Dependency. FINALLY.** But then I had a horrible reckoning, when Hayley was fit again to leave PICU we would have to go through the ward system again, back to Ward 11.

Weight Gain

**Mum was still bothered by Hayley's weight gain. She told staff nurse Sanjit Moore and student nurse Simone that she was worried.**

**"Hayley's gained weight**

**I don't like it**

**I am not happy with it.**

**She's very bloated**

**WOULD HER HEART AND LUNGS BE WORKING PROPELY?"**

**NO ANSWER**

**"Look her wee ankle is swollen"**

Simone looked at it.

Simone told mum she had leukaemia treatment when she was young and her ankles would swell when she had a line in. That was probably what was wrong.

Staff nurse Sanjit Moore agreed with student nurse Simone

Mum said

**"BUT HER WEE FACE IS BLOATED"**

**Nobody answered, they didn't seem overly bothered. They carried on with what they were doing.**

Junior Sister Sheila Bennett came in to see Hayley. I was really comforted at this stage because everyone was starting to rally around and help Hayley. Sheila Bennett removed Hayley's nasal prongs, stuck down her NG tube and helped us fix Hayley's IV fluid line

because it kept occluding all the time.

### **Special Note:**

Hayley was always having problems with her lines; I always told everyone that she had to get a Brovine line (not sure of medical term) in when she was in Belfast and it could take up to 1½ hours to put a line in and 9 times out of 10 they had to call for someone who was more senior and experienced. Her left ankle was swollen and puffy from where the IV fluids had collected when her line had failed that morning. We had to keep asking Sheila Bennett and Sanjit to help us fix Hayley's line because it kept occluding.

### **ISOLATION**

1.00pm:

My dad and I watched Junior Sister Sheila Bennett talking to staff nurse Sanjit Moore and Simone (the student nurse) outside the door; she looked quite serious and suddenly reached out for the ISOLATION sign, turned it around, shut the door and walked off. Sanjit came in wearing a plastic apron, she told us that they were worried about infection and mentioned something about swine flu. They had to take an MPA swab (Correction Medical notes NPA.) and we were now officially in ISOLATION. We had to stay away from the common areas in the ward to avoid infecting any other babies. Mum, dad and I were very confused and scared. Hayley did not have a temperature or fever or any symptoms of the swine flu so it was a total shock but as we didn't want to cause any harm to the other babies, we just did as we were told. I couldn't believe it, why did this have to happen? One minute everyone had rallied around and the next minute we were in an even more vulnerable position. How could we get help if we weren't supposed to leave the room? How would anyone hear the alarm if the door was shut?

### **VERY IMPORTANT**

I bumped into Staff Nurse Sanjit Moore the day after Hayley died (12/11/09) in town outside the hospital. I told her Hayley died, she was very kind, gave me a hug and cried with me. I don't know why I brought it up but asked her why we were put in ISOLATION, Sanjit said that she had been told Hayley had a "cough and a cold". HAYLEY HAS NEVER HAD A COUGH OR A COLD IN HER LIFE. Check her GP medical records. I believe it wasn't Hayley, but me that was put in ISOLATION to SHUT ME UP.

Medical Notes confirm NPA clear - 12/11/09

### **Special Note:**

I talked to SHO Pam later that night; she asked me **why the hell were we in ISOLATION?** I told her I thought I was being punished because I told everyone all morning that Hayley had been neglected. She went to check straight away and when she came back she said that she had written on the doctor's notes for staff to be on the lookout for any symptoms that could be SWINE FLU. There was a case in the leukaemia ward and she was being really careful. I didn't quiz Pam any further because I trusted her, although I did feel uneasy and suspicious.

1.30pm:

Saw Physio come up to the door, they saw the ISOLATION sign and kept walking. We had an appointment at 1.30pm. I was gutted.

3.00pm:

I went to the nurse station and asked if Hayley was being left until last for physio because she was in ISOLATION. Sanjit said she would beep them straight away.

3.10pm:

Member of the surgical team came to cut open Hayley's wound. Sanjit was shocked because she had not seen a wound like it before. Dr Stumper came in to look at the wound and asked if it was better or worse, I wasn't really sure because Dad knew more so I asked him - it still looked awful but it wasn't as red and raised on the outside. There was supposed to be a wound care chart attached to Hayley's notes so I thought everyone would know how it was, I wish now I had got Dad to take photos.

Mum jumped up when she saw Dr Stumper and said "what about Hayley's lungs?", he looked irritated "Physio", "will that make her better?", "yes", "Physio" he shouted, then left. Poor mum said she had never seen such a look of utter contempt in all her life.

3.20pm:

Physio session was excellent.

### **Special Note:**

Hayley's IV line kept occluding all day, at least 4 to 5 times an hour. We tried our best to fix it ourselves, we felt uncomfortable leaving the room to get help because we were in ISOLATION. Mum, dad and I took it in turns to go out to ask for help, I was worried that being in ISOLATION was seriously jeopardising Hayley's access to immediate help and support because we were scared to leave the room.

I couldn't believe it, I had felt really comforted when everyone had rallied around that morning but now we found ourselves in an even more vulnerable situation.

#### 5.30pm – 6.00pm:

Talked to SHO who told me that Hayley's lung was not serious \* **Medical notes confirm that was a lie, MASSIVE CONSOLIDATION left lung, volume Loss right lung.** She stood at the door and didn't come in. I told her Hayley was lying in a head box in a complete mess, it should never have happened; I told her I didn't trust the hospital. She told me she had to go and organise a handover and started walking off to which I became really agitated and told her I was so sorry for wasting her time and said "go ahead, leave". She then back tracked and kept saying "sorry, sorry". She then came into the room and kneeled down, I told her to get up and talk to me adult to adult. I told her "all you've done is dismiss us and treat my parents like shit". She did try her best to pour oil on troubled water. I held the door open and told her to just go, I didn't want her to be late for handover. I wasn't proud of my behaviour.

Sanjit witnessed the whole thing.

#### 8.00pm:

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 CPAs but it sounded serious.

#### 8.00pm – 8.30pm 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.

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, 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.

8.30pm:

Hayley got new antibiotic.  
Obs back on every hour

9.30pm:

Half IV fluids and half milk

12.00 Midnight:

Went to nurse's station to tell staff nurse to put 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 so 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 apologized 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 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%

**11/11/09**

7.00am:

Hayley was put back on 100% milk feed \* Medical notes state Hayley was put on 100ml / kg continuous at 2:00am 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.

7.15am:

I got the staff nurse to stop Hayley's milk feed; I said she was working harder to breath. It took 15 minutes to get her stats back up to 91.

Pam came straight away, checked Hayley over and said she was working a little harder and would put her back on half IV and half milk. She talked to Hayley and called her a pet name; she was both professional and kind.

7.30am:

New staff arrived for change over. I always liked the change over in the morning as there was a new energy and fresh faces, it was noisier too. I hadn't slept in 38 hours but mum and dad would be here at 9.30am so I was relieved. I looked at myself in the mirror, realising I looked dreadful, I grabbed my wash bag but then put it down again as I didn't want to leave Hayley alone in the room with the door shut. I only took my eyes off her for a second.

### **I HAD A TERRIBLE FEELING**

I turned around and saw Hayley really gasping to breathe, her stats suddenly dropped to 65, the left side of her mouth was puckered out while the right hand side was completely sucked in. Her eyes were panic stricken and they started rolling back in her head. I could see her neck was starting to collapse in. At first I thought she was choking but when I threw the head box off and put her on my lap to thump her on the back, I knew within seconds we were in serious trouble. I had the oxygen pipe right under her nose but it wasn't giving her any relief.

### **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 get help but I felt sick, she was scared and struggling and I was running off. Within seconds I had her back in the bed, put the head box on, attached the tube and ran for the nurses who came straight away. One nurse started putting the oxygen mask on but the other nurse looked shocked, said "oh dear" and called for PICU. They tilted Hayley's head back to open her airways; she looked awful, like a fish out of water gasping for every breath. She started turning blue. Hayley was in so much trouble, she needed help straight away. I had a terrible thought because we are in ISOLATION does that mean they won't let us into PICU. We were told not to go into common areas, when they come do they have to put the plastic aprons on? I should have pushed the ISOLATION issue more with Pam. I had let Hayley down.

All of a sudden PICU were in the room, they didn't put the aprons on thank God. There were about 15 people in the room all to help my wee Hayley. I recognised the lovely Dr Rich, I said I was very happy to see him but very sad. When he went to put the long tube down he commented on Hayley's new front teeth, it was the first time I had seen them. Dr Rich asked for adrenaline, I knew her line probably failed as I'd heard someone say something about her line being out. I was always worried about Hayley's lines failing and now that she was in serious trouble I really feared for her life. Every time Dr Rich asked for adrenaline I kept getting squirted in the fact, I think he asked for it at least 4 or 5 times and it's only now that I think about it that the adrenaline was spraying over my face instead of going straight to Hayley's heart.

The medical notes do not mention that Hayley did not receive her life saving medication. She died with no pain relief. Dr Zdenka kept saying sorry each time the adrenaline sprayed over my face.

They frantically tried putting lines in. All I could think of was if only I had made an official complaint on Tuesday morning I could have pushed to get her into PICU or at least High Dependency. All the time I held Hayley's hand, stroked her hair and told her she was the best girl wee girl in the world. I kept repeating it over and over again. About 8 different people took it in turns to work at resuscitating Hayley; they worked on her chest until their hands hurt. The colour was draining from her body and she looked really helpless.

I could see the monitor flashing red – CARDIAC ARREST. Her wee hand was limp; I wasn't sure if it was the life draining out of her body or if they had given her a shot to paralyze her when they put the long tube down. I kept squeezing her hand to see if she would respond. Her wound was leaking pus from the pressure of the resuscitation. They took the bars off the top of her bed; I helped pass it out of the room and quickly made sure that underneath the bed was clear so we could make a clean exit to PICU. I grabbed my little girl's hand again and just kept talking to her. I really wished we were in PICU, there would be so much more support.

All I could think about was Hayley being dumped at the door.

At 15 minutes the lovely Jackie Clinton came in and asked if there was anyone she could call.

At 17 minutes they stopped working and checked her vitals. I asked the doctor "how long do we have for brain activity", he was very kind and said we still do have time. They resumed resuscitation.

At 18 minutes the doctor said he could feel her heart. Numbers suddenly appeared on the monitor, it was like the lotto, then he said something about "collapse".

At 19 minutes I noticed that everyone had stopped looking at Hayley and had started looking at me with pity in their eyes, I also noticed that Hayley had soiled her nappy. One of the doctors said “come on sweetheart” while he worked on my Hayley. I knew we were in serious trouble and the doctor being kind confirmed my worst fears.

At 20 minutes Adrian put his hand on my back and said “sorry mum, we’ve lost her”.

All I could think about was I’m not a mum anymore because Hayley’s dead and I really loved being her mummy. I thanked PICU for helping Hayley and said I really appreciated all their efforts. They asked if they could do anything to help, I told them to let me be alone with Hayley so I could give her a cuddle and turn the lights off on the way out because she always hated bright lights. I covered her up and wrapped her up tight in her wee bunny blanket. I called my husband Bobby in Australia and told him our wee girl was dead. I put the phone to Hayley’s ear so he could tell her he loved her and say goodbye while she was still warm.

I believe that Hayley’s death could have been prevented. I do not want her death to be in vain and for her to be forgotten. I truly believe that if the medical team had listened to me her mummy and my mum and dad; her grandparents, she would still be alive today.

I request that this letter be officially documented with Hayley’s medical records \* **No one bothered to put my letter with Hayley's notes. They didn't listen when Hayley was alive and suffering. They still refused to listen now that my wee girl was dead.** Hayley’s story might make a difference and help others. I know it won’t bring her back but it will give me some comfort. I would like to make a special mention about the Clarke Clinic at the Royal Victoria Hospital in Belfast. Hayley spent the first 9½ weeks of her life there and we felt very protected, nurtured and safe. Even though I was a new mummy and was learning every day, I was made to feel a valuable part of the medical healing team. The nurses would always say “you’re her mummy, you know best”. If I had any concerns they would organise a consultant, doctor, dietician etc. to listen to me and work with me.

Everyone worked so hard for Hayley and I am so grateful to them all, especially Dr. Casey. I respect and admire him as a medical professional but also as a person. The thing I loved most about him was even though he was very senior and had years of expertise and experience, he also knew he did not have all the answers and it was this humbleness that I respected. I would also like to thank lovely Rosie and wonderful Catherine who checked on Hayley on our satellite link. Thank you for being a big part of Hayley’s life and I will miss you both dearly.

I did my best to fight for Hayley. We came so close.

In loving memory of Hayley Elizabeth Fullerton  
06/10/08 – 11/11/ 09



**WHAT HAPPENED AFTER HAYLEY DIED**

**RE: NHS COMPLAINT**

**HAYLEY ELIZABETH FULLERTON**

**06/10/08 – 11/11/09**

## WHAT HAPPENED AFTER HAYLEY DIED

I kept a diary of all meetings, conversations and events related to Hayley's death.

11/11/09

Approx 10am:

Justine Kidd informed me that the hospital would take care of Hayley, I interrupted her; "no way, under no circumstances is the hospital to touch Hayley, I do not trust them". I want somebody from outside and completely independent".

"Hayley was neglected and overlooked when she was alive and suffering, I'll be damned if she'll be neglected and overlooked now that she's dead". "You're not to do anything without my prior knowledge and permission; I have no faith in the hospital"

10.10am:

Justine came in with Zdenka. I felt sorry for Zdenka and said "why did they pick on you, you did your best for Hayley". She showed me her notes and turned over the page highlighted where she had written "mum isn't happy". I wanted to sit down and talk it over but I needed to wash and dress Hayley as that was more important. Justine brought in the staff nurse from night shift and the Irish Sister. The staff nurse came up to give me a hug, I didn't really want to but I did so only because she looked awful and she needed me to give her a hug. She hadn't taken me seriously when I told her Hayley had been neglected and I was really worried about her. The sister went to give me a hug but I put my hand out and told her to back off. She had scared me on Monday night (09/11/09 at 8pm) as she came into the room completely ignoring Hayley and I. She took the staff nurse over to the opposite end of the room, whispered to her so I couldn't hear and then turned on her heels and walked out again, completely blanking Hayley and I. I WAS HORRIFIED I didn't know what was going on? I had told staff nurse Hayley I was very worried about my wee girl and thought something was wrong. Had the Sister found something out but didn't want to tell me? I asked "what on earth was wrong". I then found out that the Sister had a secret stash of sweets and she didn't want the other staff to find out, she came in to tell Staff Nurse Hayley where they were. I couldn't believe it! I had given the Sister a big box of celebrations earlier on to share, she didn't say thank you but just said "we need more". She was just being sneaky, leading me to believe something was wrong with my baby. I had given her the sweets to sweeten her up; I thought that she might glance in and check on Hayley. When she first appeared I was excited to see her. I was so DISAPPOINTED when I found out the truth. What an insensitive, stupid and unprofessional way to behave.

The new Sister asked if we would like some foot and hand prints of Hayley which I thought was a beautiful idea and found really comforting. She came back with orange, blue and

purple, I told her Hayley was a GIRL, where was the pink? She said she couldn't find any. I asked her to look again; the Sister replied it would probably take a long time. An hour and a half later she came back with a pink pad smudged with purple. It was the best she could do. I realise this is not medically related but it highlights the careless attitude of some of the staff. I FOUND IT DEMEANING TO HAVE TO ASK FOR PINK INK FOR MY DEAD BABY GIRL.

SHO Pam Dawson came in, I gave her a big hug and told her she was great "please don't worry, you did the best job looking after Hayley"

### **RAINBOW ROOM**

We all took turns hugging Hayley. We told Justine that we were very upset with Dr Stumper. When mum jumped up and asked about Hayley's lungs on Tuesday morning he looked at her with utter contempt. She was a scared granny worried about her granddaughter. He made her feel like shit on his shoe. But mum was right about Hayley's lungs and no one did anything until they started collapsing. Justine talked to Dr Stumper and said he was more than happy to talk to us. We said we were just too upset now and wanted to spend time with Hayley.

### **12/11/09 Approx 11.30am**

I went back to WARD 11, I needed answers. I walked up to the nurse's station and told them **HAYLEY WAS NEGLECTED AND OVERLOOKED AND THERE WAS NO NEED FOR HER TO DIE.** I wanted to make a formal complaint.

### **Special note:**

I was very conscious and aware of my behaviour. I talked quietly and didn't get emotional, nor did I cry. I knew I would be judged on my actions. I wasn't interested in raising a scene; I only wanted to be heard and to speak up for my DEAD BABY. I also didn't want any unseemly behaviour to discredit anything I said and I didn't want to scare the other parents on the ward either. I knew I was making a serious allegation and I had to be professional even though my heart was breaking.

I told everyone at the nurse's station I didn't want to dishonour Hayley's memory by doing anything she would be embarrassed about. I wanted everyone on the ward to know I believed that she would still be alive today if they had have listened. The Sister tried to get me to talk to someone more senior. I said "this is where she died; this is where it needs to be addressed, from the grass roots up. I wanted everyone to see the suffering on my face and remember Hayley and maybe stop and think.

Lying in bed all day and crying wasn't going to honour Hayley. I didn't want Hayley to be swept under the carpet or be reduced to a memo about lessons being learnt and empty apologies. I stayed for 1½ to 2 hours, using the Ward Manager's office like an interview office as Karen Burns allowed me to temporarily take it over. She was polite and professional and recommended PALS to me. I then sat outside the Ward Manager's office just waiting to see who else was on duty that day. One of the lovely registrars from PICU

came and sat with me, he said he was so sorry and asked what had happened. He had walked past Hayley's door about 5 days ago, gave me a big cheesy grin, put his thumbs up and said:

**“CLOSEST TO THE DOOR, YOU'RE ON YOUR WAY HOME”**

I told him we were dumped at the door and neglected and all his hard work had gone to waste! Ben Anderson appeared and stood over me, I told him Hayley had been neglected and she didn't have to die. He nodded his head and went “ahmm, ahmm” with his mouth pursed shut. I told him “I know you've been trained to nod your head and agree with everything an agitated and aggrieved parent says”, he just kept nodding. Justine appeared and sat down beside me, I said “I knew someone would call you” she replied “oh no, I was just passing”. I told Justine she was a lovely lady, very softly spoken but no fire in her belly. It was my baby who was dead and I needed to speak up for her myself. I had to do it on my own. I asked her to leave but she didn't leave. I looked at Ben, I asked him why he didn't take us seriously, why didn't he do something? He kept nodding his head agreeing. I said “do you have anything to say?” he looked me straight in the eye without blinking and told me:

“HAYLEY WAS FINE”  
“BEN, HAYLEY IS DEAD!”  
He just kept nodding.

**WORDS FAIL ME**

I shuddered; I found this statement dangerous and disturbing, especially as he said it in front of his medical colleagues. How could Ben still believe that Hayley was FINE? How could he hold firm to his medical opinion and refuse to face facts. My baby was dead. He didn't offer any condolences, showed no empathy or sympathy, he had no regard for the impact his statement had made. He was completely devoid of any emotion. I could understand if he wanted to cover himself and safeguard his job as that is perfectly understandable and human but I never expected “HAYLEY WAS FINE”. That statement was wrong on so many levels.

Ben was going to be Hayley's doctor in Australia, we thought he was a terrific find but now I was shocked, he was cold hearted, displayed anti-social behaviour and was completely out of touch with reality. FROM ONE EXTREME TO ANOTHER.

There was one member of the medical team who did restore my faith in humankind. When I told them that I believed Hayley had been overlooked and neglected and there was no need for her to die, they started crying and said “I completely accept your criticism” – TWICE. They said they were so shocked when they found out Hayley died. I was grateful for their courage and integrity, I told them I was at peace with them and knew that Hayley's death had not been in vain and they would not make the same mistakes again. I told them to please listen to the family because they know when something is wrong with their baby, even though they are not medically trained. I did not disclose this admission in my original letter because I told them it was a private conversation. I did not want them to be made a scapegoat because they had the integrity to face up to their responsibilities, BUT NOBODY

**ELSE DID. However, now it has become a terrible burden and I need everyone to know.**

I saw Dr. Stumper but didn't talk to him, he upset mum so I thought it was more fitting she talked to him directly, but poor mum didn't leave her room for days, she hadn't the heart for anything. She kept saying the look of contempt on his face would "haunt me til the die I die"

**JUST REMEMBER THAT IT DOESNT TAKE MUCH TO OFFER A KINDLY WORD TO A TERRIFIED GRANNY.**

My mum is torturing herself because no one listened to her when she asked about Hayley's lungs. She was devastated when she came in on Tuesday morning and Hayley was in the head box with 5 litres of oxygen because her lungs were collapsing and consolidated. She knew more than the doctors about Hayley's lungs but she was dismissed and treated poorly.

Text message from mum to me at 8am on 10/11/09: *"I have been asking and asking about her lungs; doctors, nurses, everyone. Not surprised"*

### **13/11/09**

I rang Justine Kidd; she asked me if I needed anything to give her a call. She said that I was very brave to go into Ward 11. I said Hayley was the one who was brave, not me; I had to do what was right by Hayley. She said PICU thought I was very strong but I had to be strong for Hayley, she needed me. I asked her to fax me the doctor's notes that I was shown when Hayley died; she told me that the notes would be hard to read, I said it was fine. She told me there were medical terms I might not understand; I said it was no problem. Just fax it. She said that the hospital didn't have copies and it was in the hands of the coroner. I said Bobby had just flown from Australia, he didn't understand what happened to Hayley and all I had to give him was the baby gro she died in and a lock of her hair. She told me to contact the coroner directly, she was very polite. Justine was normally amazing; this was the only time she didn't help.

### **16/11/09**

I rang PALS and talked to Carmel who was very kind but sounded scared. She said my case was very serious and would have to talk to supervisor Alison Stanton. Alison was in a meeting. She referred me to POhWER.

### **17/11/09 Approx 8.00am**

I bumped into a PICU nurse outside the coroners. I missed Hayley and was walking past to be a little bit close to her. I told the PICU nurse what happened to Hayley, she asked me where Hayley died, was she in High Dependency. I told her no, she was dumped at the door. She looked horrified.

I saw Ben walking past and ran up to him. I told him I kept thinking about what he said and I couldn't reconcile myself or believe what he said, I couldn't make peace with it. I repeated

what I had said previously in Ward 11 about neglect and there was no reason for Hayley to die. I had a letter complaining about him and he could read it. I asked him to say something, anything. He told me he was “shocked Hayley died”; I told him “I wasn’t shocked when Hayley died”. We were outside the hospital now, I told him it was probably embarrassing for him to be seen with me and to go ahead on his own. He stayed where he was. I told him when I needed everyone to listen to me they didn’t take any notice but now Hayley was dead, no one would leave me alone. I knew it was probably the last time I would see him, I gave him a big hug and wished him a beautiful life in Australia and asked him to listen to the family when they say something is wrong. I said I was at peace now. I needed to forgive him or I would end up hating him forever, I needed to heal, not hate. All I could think of was how excited my husband Bobby was when he thought he was getting his little girl back.

I had found out Hayley had a heart condition when I was 23 weeks pregnant, I was on holiday in Ireland, I had lived in Australia for 12 years with my Aussie hubbie. I was scared when I found out about Hayley and Bobby and I decided it was best for me to stay in Ireland as we trusted Dr Casey. Bobby flew back and forth to Australia 18 times for 21 months. I chose to go to Birmingham as it had the best surgeons. Dr William Brawn had saved us from the worry and stress of 3 extra ops before Hayley was 7, this is what would have happened if we stayed in Belfast.

After the corrective surgery Dr Brawn told us “she wouldn’t need another op on her conduit until she was in her late teens and if she was a good girl her patch in her VSD would last her until her late twenties, early thirties”. Our whole life was in front of us, we couldn’t wait to finally be a family together at last in Australia. I had even gone to chapel and wrote a prayer on the prayer tree and I am not a religious person. I told Ben I didn’t want to make him late for work. I had to forgive Ben or else turn into a bitter old women, but because I forgave him didn’t mean I condone his actions or relieve him of his responsibilities.

I couldn’t look at Ben any longer; I told him I didn’t want to make him late for work and to go ahead.

## **WARD 11**

Approx 8.20am:

I saw Jackie Clinton, she was very kind. All I wanted was help with everyone’s names in the letter, I told her what I had written and she listened carefully. She asked me if there was anything they could do on the ward to improve things. **JUST LISTEN**. I respect Jackie Clinton, she was sensitive and considerate, I knew she was genuinely upset and sad about my precious baby Hayley. I did say I was bothered by Junior Sister Shelia Bennett, I told her she had lied about Hayley having a “COUGH and a COLD”

9.30am:

POhWER typed up my letter. Sarah sat with me for hours as I read it out.

Approx 1.30pm – 2.00pm:

I hand delivered letter to Ward 11

**18/11/09**

I saw Justine at the Coroner's office and told her to rip up the hand delivered letter as it had a few mistakes in it. I faxed the letter with typex mistakes to her office, using the fax number she had gave me. The coroner's secretary faxed it for me. Justine was a lady, as ever.

**19/11/09**

Took my baby home, we watched them put the coffin on the plane. I had to explain to everyone what happened to Hayley. It was painful enough to lose her but the horror on everyone's faces when I told her story of neglect was just too cruel.

**27/11/09**

Rang Alison Stanton and told her I was writing up a letter of complaint. I took her email address and told her I would send a more formal letter with additional information and no typex mistakes. She said she looked forward to receiving it.

I suddenly started receiving letters from the hospital; I was confused and didn't understand why they had decided to forward letters before I had sent off my official complaints letter.

Wednesday 02/12/09 – Sympathy card from Justine Kidd

Thursday 03/12/09 – Letter from Dr William Brawn

**04/12/09**

Received letter from Alison Stanton thanking me for my complaint letter dated 17<sup>th</sup> November 2009. I FELT SICK TO MY STOMACH. Why didn't she wait? Why didn't she listen? I explained it was a painful letter to write and I was worried about making mistakes.

12.30pm:

I rang her straight away. I told her I was worried I was going to lose my opportunity to ask questions. She said she would sort it out. I told my mum what happened and she couldn't believe it. I got really frustrated and decided to write an e-mail to make sure she understood exactly what I was saying.

I am more than happy to share my emails addressed to Alison Stanton although it has come to my attention after reading the disclaimer at the bottom of her emails that it is unlawful for me to forward her private emails to me, unless she approves. However I have included my emails to her which are detailed below

### **Emails to Alison Stanton:**

**From:** [paulastevenson@live.co.uk](mailto:paulastevenson@live.co.uk)

**To:** [alison.stanton@bch.nhs.uk](mailto:alison.stanton@bch.nhs.uk)

**Subject:** Complaint - forwarding letter sent 17th Nov. as complaint letter without complaints permission. Not waiting for official complaint letter to be forwarded after conversation Fri - 27th Nov.

**Date:** Fri, 4 Dec 2009 14:47:42 +0000

Dear Alison,

Following our conversation at 12.50 pm Friday 4th Dec. 2009 in regards to my letter dated 17th Nov. 2009.

I want you to instruct your colleagues that you forwarded this letter without my permission and to retract it.

I had informed you on Fri. 27 Nov. 2009 by telephone that I had decided to go ahead with a formal complaint. I was writing an official complaints letter with additional information and would be sending it to your e-mail address the following week.

I explained the letter dated 17th had mistakes in it and it didn't look professional and I was working on a more official format.

I was horrified to find out that you had forwarded a faxed letter sent on 18th Nov. that had been sent from the Coroner's office without my knowledge or permission. It had typex mistakes on it and was in no uncertain terms meant as an official complaint letter.

I do not understand why you did not listen and wait until the e-mail was sent.

I explained I was worried about making a mistake and I found it quite painful. That is what was taking me so long.

I kindly request that you do not take any action on my behalf again without my prior knowledge or consent. I would kindly request that all telephone conversations be recorded so no mistakes like this happen again.

My complaints letter is based on the hospital staff not listening, I did not expect to encounter the same problems with the Patients Relations Manager.

I have organised for POHWER to represent me from now.



Yours sincerely

Paula Stevenson

Alison Stanton replied on Fri, 4 Dec 2009 15:15:13 – I have not included her response.

**From:** [paulastevenson@live.co.uk](mailto:paulastevenson@live.co.uk)

**To:** [alison.stanton@bch.nhs.uk](mailto:alison.stanton@bch.nhs.uk)

**Subject:** RE: Complaint - forwarding letter sent 17th Nov. as complaint letter without complaints permission. Not waiting for official complaint letter to be forwarded after conversation Fri - 27th Nov.

**Date:** Fri, 4 Dec 2009 17:19:59 +0000

Dear Ms Stanton,

The letter with no amendments had the wrong dates on it. I told you the letter dated 17th November 2009 had mistakes.

I advised you that I had to make amendments and had additional information that needed to be included.

You used your own initiative to forward the letter with no amendments without consulting me.

I asked for the opportunity to put together a more official "Complaint Letter" and forward it to you by e-mail.

This is the last duty that I will carry out for my daughter and I was worried about missing anything out.

EMT Transcription Services are typing it up for me in a professional format. It is very important to me that it is presented properly.

When you decided to present the letter with no amendments that had the wrong dates on it you did not inform me I was upset.

You did not wait for the e-mailed letter and started proceedings without checking first.

Please wait until I forward the Official Complaint Letter.

Thank you for your patience.

As I said before it is quite painful to write and it is taking me longer than I thought.

Yours sincerely,

P. Stevenson

Alison Stanton replied on Fri, 4 Dec 2009 17:32:18 – I have not included her response.

**From:** [paulastevenson@live.co.uk](mailto:paulastevenson@live.co.uk)

**To:** [alison.stanton@bch.nhs.uk](mailto:alison.stanton@bch.nhs.uk)

**Subject:** RE: Complaint - forwarding letter sent 17th Nov. as complaint letter without complaints permission. Not waiting for official complaint letter to be forwarded after conversation Fri – 27th Nov

**Date:** Sat, 5 Dec 2009 15:38:17 +0000

Dear Ms Stanton,

Thank you for your explanation .I do believe you did not mean any harm.

But the letter you forwarded on my behalf was dated the 17th November 2009. That should have indicated to you it was not my updated letter which I had promised to send to you after my phone call on Friday 27th November.

I still would like all phone calls to be recorded for both parties benefit.

I will be out of action until Thursday 10th Dec. - I apologise for the inconvenience.

Sarah Blackaby is my appointed case officer at POhWER.

Thank you.

Yours sincerely,

Paula Stevenson

There has been no further correspondence between myself and Alison Stanton.

I would like Ms Stanton to be given the opportunity to explain her position so I recommend you contact her directly. It is only fair that she is heard too. You can draw your own conclusions.

I watched my only child die in front of my eyes, knowing that not enough was done to save her. I quietly listened as a member of the medical team cried and told me “I completely accept your criticism” when I informed them that Hayley had been overlooked and neglected and there was no need for her to die. I have replayed over and over again in my head all the times that nobody listened. They didn’t do enough, they didn’t take us seriously, they

ignored a terrified mother, granny and granda, they dismissed used, belittled us and even scorned my mother. Dr. Stumper looked down on her with complete and utter contempt when she dared ask him about Hayley's lungs. They had collapsed and she was in a head box with 5 litres of oxygen. Mum had been warning everyone about her lungs but they treated her like a joke. My poor mum sat and watched in horror while her beloved granddaughter's head bobbed and whenever she drew it to anyone's attention their response was:

- "We've put it in the notes"
- "She's only catching up on her sleep"
- "She's fine"
- "we've seen worse"

### **NOBODY HEARD US AND NOW HAYLEY IS DEAD.**

Writing this letter has been a horrendous experience. Every waking minute of every day has been spent reliving the nightmare. I wanted someone to listen; I needed Hayley's story to be heard.

Making a formal complaint was not taken light heartedly. I am trying my best to move on with life and remember all the happy times. I was scared of being tied into reliving the pain over and over again. I was anxious about the complaints process whether it would cause more harm than good, I hoped for a dignified completion. I haven't even filed my official complaint letter and I have encountered problems. Please listen; I know it is very easy to get caught in the trap of who is right, who is wrong and who did or didn't say this or that or who did and didn't do whatever.

The most important thing is my beautiful BABY IS DEAD and I absolutely adored her and I would give up my life in a flash to have her back. She was my whole world and made everything so bright and beautiful. I had the best year of my life and am the luckiest person in the world that she chose me to be her MUMMY.

I have made a promise to myself to do amazing work in Hayley's name. What amazing choices will you make to honour Hayley's memory?

**IMPORTANT**

**ADDITIONAL QUESTIONS TO BE INCLUDED AS  
PART OF OFFICAL COMPLAINT LETTER**

## 1) PAIN RELIEF:

I need to know if PICU were able to administer any pain relief to Hayley in the last twenty minutes of her life. I felt her hand go limp after they put the long tube down but I had assumed that they had given her a shot that kept her still; something that paralysed her and knocked her out, something that protected her from knowing what was happening.

I have been going over in my head what happened and I am very disturbed now because if Hayley's line was down and the medical team couldn't get the adrenaline in (it kept spraying over my face) how could they administer any pain relief? Was the PICU team able to ease her pain or make her unconscious? I know she suffered for days before she died when her lungs were collapsing, I watched it but it is only now, on Christmas Day that I made the connection - LINE DOWN- No Adrenaline -No Pain Relief.

I know Hayley was scared when she was suffering her cardiac arrest at 7.30am on Wednesday 11/11/2009. I could see the terror in her eyes when she couldn't breathe and her neck collapsed in and her eyes rolled back in her head and I could see the fear in her eyes when I had to run off and get the nurse because no-one heard me cry for help because we were in ISOLATION. But I thought when PICU came they had given her a shot so she wasn't aware of her pain and suffering.

I want to know if Hayley was given pain relief, if she did receive pain relief, how many minutes did it take? What was the pain relief called?  
How long did the pain relief take to have effect?  
How would the pain relief help her; what exactly did it do?  
I want to know if Hayley was aware of what was happening.  
What would Hayley's experience have been?  
Did my baby suffer more because the line was down?  
Would she have been spared this extra suffering if she was in PICU and the back-up line would have been available?  
Would she have been aware that her mummy was with her, holding her hand and telling her "she was the best wee girl in the world"

2) **Ward 11, Room closest to door. Time: 7.32 am**

When PICU tilted Hayley's head back to put the long tube down she had a milky froth bubble on the left hand side of the corner of her mouth, it was the size of a pea, I think she had regurgitated her milk or had vomited a little. How would that have affected the effectiveness of the resuscitation attempts? I know the nurse drew out 25 ml of milk from her stomach through the NG tube before they put the long tube down to help Hayley but her sharp drop in stats to 65 from 92 came about 15 minutes after the nurse stopped her full milk feed at 7am.

Previously Hayley had been on half IV fluids and half milk. Could her slight vomiting or choking have triggered her respiratory distress, (her lungs had been severely affected the night before because she did not receive physio when required) lung collapse then cardiac arrest and death.

When I first noticed Hayley was in trouble at 7.30am I did think that she was choking and had immediately got her out of bed and placed her on my lap to thump her on the back but when I saw her neck sucking in and collapsing I ran for help.

I didn't notice any milk froth then, only before they went to put the long tube down.

Did the milk trigger her decline?

If the NG tube was in the wrong place would that have compromised her already weakened lungs?

3) **HEAD BOBBING**

I have been talking to medical professionals and been reading medical documents and articles in regard to this subject. I would like my questions to be answered by the four medical staff listed below:-

Dr William Brawn

Dr Stumper

Dr Ben Anderson

Dr Zdenka Reinhardt

I have to reiterate part of the Official Complaint Letter to raise my specific concern:

From Friday 6th November until Wednesday 11th November (the day she died) Hayley's condition rapidly deteriorated. She slept all day and all night, was extremely lethargic and depressed, whereas previously she was playing and alert and happy. She was too exhausted to eat, she hardly tolerated her gravity feed, whereas previously she was guzzling down bottle feeds, eating beef stew, mango and ice-cream, munching merrily away on toast and Cheerios. Her whole abdomen was sinking in when she breathed, the recession became greater and greater each day, whereas previously she was on 0.2 litres of oxygen and her breathing was relaxed.

I informed Dr Ben Anderson on Friday that I was worried about Hayley's sudden decline. My parents told Ben on Saturday and Sunday and Monday that they were worried about Hayley having to fight for every breath and the worrying state of her lungs. He kept saying Hayley was FINE.

Please read the following article:-

### **SUBJECT - RESPIRATORY DISTRESS**

*An increased work of breathing - typified by retractions, grunting, head bobbing and nasal flaring is the most specific indicator of respiratory distress*

*Fatigue is the most specific indicator for impending respiratory failure*

*Respiratory failure is the number one cause of paediatric cardiac arrest. Bradycardia is almost always caused by hypoxia in children and is an ominous and late finding.*

### **Question:**

Do you agree or disagree with this information? - YES/NO

Please explain why you agree or disagree - for example, it follows the same guidelines as you were trained in - you know from experience.

Why did Dr Ben Anderson ignore these warnings and allow Hayley's lungs to collapse and for her to suffer cardiac arrest and die?

The warning signs are blatantly obvious -do you agree or disagree? Give me an explanation.

Please read the following statement printed in the Advanced Paediatric Life Support:

### **The Practical Approach**

*Golden Rule of Paediatric assessment:  
ALWAYS, ALWAYS LISTEN TO THE PARENTS  
If they are concerned about their child's condition so should you be.*

I only need Dr Ben Anderson to answer this question.  
Do you agree or disagree with this question?  
Please give a detailed account explaining your decision.  
Back it up with evidence -for example findings based on personal experience or proven medical findings.

### **Personal Point of View**

When I read these particular articles I felt sick to my very core. I am disgusted by the lack of treatment and failure to diagnose Hayley's condition. It seems pretty basic and obvious to me and I have no medical training. If Dr Ben Anderson was so unaware of the clinical clues that Hayley presented to make a responsible evaluation and deduction to treat a life threatening condition, why then did he also fail to respond appropriately to the immediate family's pleading and begging that Hayley was very sick. My father asked him three times -"is Hayley's condition life threatening, does she require further surgery?" And my mother's pleas "her lungs, her lungs I'm embarrassed asking about her lungs".

Question to all four doctors:  
Do you find this conduct acceptable? Yes/No  
Please explain your decision

### **Closing Comment**

The more information I find the more disillusioned and disappointed I become. Hayley's death becomes more and more tragic because it could all so easily have been avoided. It just seems like one big sick joke. My whole family and I were so elated that the surgery had gone so well. You did a great job Dr Brawn, thank you. All your dedicated work was destroyed.

The experience on Ward 11 has completely traumatised my mother, she said it was worse than being in a third world country because at least in a third world country you know that conditions and resources are basic but you hope that people will do their best with limited facilities/equipment but your hospital had world class facilities in abundance but was deficit in care.

Hayley survived the operation, she survived her lung being accidentally collapsed, she was over all the huge challenges and I was extremely proud of my little girl. I



never thought for a second that a social issue would be her ultimate downfall and result in her death. How can you function as a doctor if you have an apathetic and arrogant attitude and dismiss the pleas of terrified family members that something is seriously wrong with their child?

When you bury your parents you bury your past  
When you bury your child you bury your future

I organised Hayley's headstone today, do you know how difficult it is to get a pink granite headstone!

### **Hayley Elizabeth Fullerton – Medical records**

From: [paulastevenson@live.co.uk](mailto:paulastevenson@live.co.uk)  
Sent: 16 January 2010 13:57:04  
To: sarah Smith ([sarah.smith@pohwericas.net](mailto:sarah.smith@pohwericas.net)); jon hoskin ([jon.d.hoskin@birmingham.gov.uk](mailto:jon.d.hoskin@birmingham.gov.uk)); [laura.preston@bch.nhs.uk](mailto:laura.preston@bch.nhs.uk)

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MEDICAL RECORDS – 16/1/2010

We received Hayley's medical records yesterday.  
My family and I are numb with pain.

My mother is distraught, she is devastated nobody had listened "her lungs, her lungs what about her lungs".

"I am embarrassed asking about her lungs".

I saved a text message she sent me after I told her Hayley's lungs had collapsed during the night, and reads..."I have been asking and asking about her lungs Doctors, nurses, everyone not surprised".

Message received 8am 10/11/2009.

We truly believed on Tuesday when Jackie Clinton had asked if I wanted to make complaint that everyone had finally taken us seriously and had listened and responded.

Everyone said they were shocked when Hayley died, my family and I watched Hayley suffer day after day from from Friday 6<sup>th</sup> November 2009. It was obvious to us.

Dr Ben Anderson witnessed her severe respiratory distress from Friday to Monday and he heard my families pleas.

I need answers. I deserve answers. I do not want a summary from the complaint committee on their findings.

My family and I believed our love and dedication for Hayley would impact on the staff. We were by her side 24 hours a day 7 days a week and we knew her every little gesture. We knew our little Hayley was in trouble. WE TOLD YOU ALL.

Hayley was overlooked, neglected and suffered while she was alive. Do not overlook and neglect her now she is dead.

Do the decent thing and answer our questions.

Mrs Paula Stevenson

Mr Bob Fullerton

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# CONCLUSION

Hayley's Little Life

One year, one month and five days

Is a Little Life cut short

One year, one month and five days

Is enough Love for a Lifetime

Love Always

Mummy & Daddy

Bobby wrote this poem for his little girl.

Thank you Bobby for giving me the gift of Hayley and the best year of my life. I love you.