Scottish Hospitals Inquiry

Witness Statement of

Louise Cunningham

WITNESS DETAILS

1. My name is Louise Cunningham. I was born on [redacted]. I am [redacted] years old. I work [redacted] .

2. I am the mother of [redacted]. [redacted] date of birth is [redacted]. [redacted] passed away on [redacted] when she was 3 years 6 months old.

3. I live with my two sons, [redacted] and [redacted], in [redacted], [redacted].

OVERVIEW

4. My daughter is [redacted]. [redacted] was diagnosed with Stage 4 High-Risk Neuroblastoma in March 2017 when she was 2 years and 8 months old.

   [redacted] was treated in the Royal Hospital for Children (RHC) between March 2017 and [redacted], when she passed away. [redacted] was an in-patient during this time, and only attended as an out-patient for approximately 4-5 weeks out of the 10 months she was a patient at the RHC. With the help of my solicitor, I have prepared and provided the Inquiry with a timeline, showing the dates on which attended hospital and the wards where she was treated. The timeline is attached to this statement at appendix 1 (**LC/01**) and I confirm that it is accurate to the best of my recollection.

5. [redacted] spent time in wards 2A, 2B, 2C and 3A of the RHC. Ward 2A is part of the Schiehallion Unit. The Schiehallion Unit treats children with cancer. I stayed with [redacted] during her time as an in-patient and I can speak to the experience which I had with [redacted] on these wards.

FAMILY BACKGROUND

6. I live with my sons in [redacted], [redacted]. [redacted] is my youngest child, my oldest son, [redacted], is [redacted] years old and my other son, [redacted], is [redacted] years old.

7. [redacted] was crazy, absolutely crazy. She was always such a happy, go lucky wee girl. She had no fear whatsoever, not one bit of fear in her body until she started to become unwell.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE RHC

Admission to hospital: March 2017

8. We had a couple of admissions to hospital during March 2017, where they told me [redacted] just had some sort of viral infection and then discharged her. The first time we went in they discharged us after a few hours and then the second time, on 12 March 2017, they kept her in for a couple of nights and then discharged us. I was told at that time that [redacted] haemoglobin level was slightly low but that it was fine and not to worry about it as that's what happens with a viral infection.

9. [redacted] was still not 100 per cent so on Thursday 16 March 2017, I took her back to the RHC. I went in first thing in the morning and later on they moved us to the Clinical Decisions Unit (CDU). A few hours after that we were moved up to

ward 2C. They didn't know what was wrong with her but then about half past one, quarter to two in the morning, a few doctors and a nurse came in and said that [redacted] had to go for an X-ray and a CT scan as they'd found something in her blood.

10. We went for the X-ray and the CT scan and were told then that her liver looked enlarged. They also asked if [redacted] had had an accident, like a bang to the head. I said she was constantly banging her head, she had two brothers and she acted like she was a wee boisterous boy because of them, but the nurse said no, this would be like a car crash trauma.

11. I was then left with no further explanation and later that morning [redacted] was taken for an ultrasound. A wee while after that a doctor said that they'd found two masses in [redacted] stomach and that she had basically no platelets in her body. Her blood wasn't clotting at all, it was just kind of floating about.

12. It was at this point they said they were moving her to ward 2A, the oncology ward. This is known as the Schiehallion unit.

[redacted] initial treatment Ward 2A: March 2017

13. Within 24 hours of [redacted] being admitted to ward 2A on 17 March 2017 she deteriorated quite a bit. It was as if [redacted] knew there was something wrong with her and that we'd all now found out too.

14. The doctors put her onto a platelet transfusion, a blood transfusion and they gave her a morphine pump. It got to the stage that I couldn't even change her nappy without her having two pushes of the morphine pump for the pain. I think her body was trying to fight it itself.

15. I spoke to Dr Ronghe, [redacted] consultant, that day and he said [redacted] needed to get a DMSA scan done, a bone marrow aspiration done and an MRI scan. The

DMSA scan is similar to an MRI, but you get a dye injected into you and it takes around five hours. The dye illuminates neuroblastoma in the body. He said that because this was the Friday and it was a skeleton staff on, so things would be getting done in dribs and drabs, he wanted to just keep her pain at bay and get some bloods into her over the weekend and start afresh on the Monday.

16. I agreed to that so on Monday 20 March 2017, [redacted] went down to the MRI Department on the first floor. She was there for five and a half hours getting the scans done. She was continuing to deteriorate and although Dr Ronghe had had an initial look at her scans, the official reports hadn't come back yet. As part of these investigations, [redacted] had a biopsy taken of her tumour that was sent down to Great Ormond Street Hospital for analysis. The results of this biopsy that came four to six weeks later showed that [redacted] had an N-MYC gene tumour which is a very rare tumour that only one in a thousand are born with.

17. [redacted] had surgery during that first week to get her central line in. This involved them doing an ultrasound of her neck to find the best vein and then they put the line in through the neck into the main artery in her body. At this point she was just getting more and more unwell.

18. On Thursday 23 March, Dr Ronghe said that he was really concerned that

[redacted] had stage four high-risk neuroblastoma cancer and that although he didn't have the results of her biopsies, it was his opinion that [redacted] needed to start chemotherapy right away or she might not see it through the weekend.

19. I accepted what he said and [redacted] started her chemotherapy straightaway. This was her first round of seven of the rapid COJEC chemotherapy. Each round lasted three or four days. Dr Ronghe said that she would pick up a wee bit after her first round but [redacted] was still really, really unwell.

20. Around about the 26 March 2017 [redacted] had her first line infection which was roughly ten days after her admission. [redacted] had a high temperature and she wasn’t eating or drinking. The hospital staff didn’t say what the infection was, just that it could be chemo related or that it could be coming from the actual tumours. They gave her antibiotics at first but these didn’t work so they ended up taking her back down to surgery to get her line taken out.

21. A couple of days later they put a new line back in. You have to wait at least 48 hours after getting a line taken out before a new one can be put back in but within a day or two [redacted] was like a new girl. The infection had basically been making her more unwell, but she started to laugh again and she wanted to eat and things. Every time that [redacted] had to get her line removed and replaced, it was two separate surgeries under a general anaesthetic.

22. [redacted] official diagnosis of high-risk stage 4 neuroblastoma was confirmed in the week beginning 27 March 2017, though I cannot remember exactly when.

Experience in Ward 2A: April 2017 – Rhinovirus

23. Sometime in April 2017 ward 2A was shut down for something called rhinovirus. We were shut down for nearly two weeks. This meant that we weren’t allowed out our rooms, we weren’t allowed visitors and we weren’t allowed to use the parents’ kitchen.

24. The nurses said that some kids in the ward had tested positive for rhinovirus and to prevent it spreading, the best thing they could do was shut down the ward. I had no clue what it was but obviously when they were putting us into lockdown, I knew there was something bad going on so you just listened to the staff and did what they asked.

25. I know we were definitely in lockdown on 16 April 2017 as my ex-partner's sister had come from Ireland to see [redacted]. They did let her in for about 20 minutes because she'd come a long way but at that time we weren't allowed out our rooms.

26. That was really hard going. [redacted] didn't understand why she wasn't allowed out her room and why she wasn't allowed to go to the playroom and I couldn't go to the kitchen and make her a tin of soup or pasta, as these were things that I knew she would eat. [redacted] was really close to me and she wouldn't go with anyone or let anyone else stay with her so I stayed with her every single day and night. I therefore had the strain of that situation and also a two-year-old child who couldn't understand why her gran and her brothers couldn't come up and see her.

27. I also remember at that time we were told to remove everything from

[redacted] room. At first when [redacted] was admitted to the ward, we were told that we could make [redacted] room her own and bring in anything she needed or wanted.

[redacted] had some teddies, her wee pram and doll and things like that, just a wee bit of home. But after that lockdown, infection control and health and safety staff came into the ward and made us send everything away, even down to pictures and cards. [redacted] was allowed to keep one or two things but the rest had to go. It was all removed and taken home.

28. It was at this point I thought, "What's going on here?". Shortly after that we started all being moved to different rooms. The nurses were using excuses like another patient needs a room closer to something or, other times we were told that we were getting moved because the room was getting deep-cleaned. The staff didn't say why the room needed deep-cleaned. We moved rooms a lot.

Experience in Ward 2A: April 2017 – September 2017 – [redacted] Chemotherapy Treatment

29. When [redacted] first started her chemotherapy treatment in ward 2A, we were allowed to go out and about in the ward. It took a wee while for [redacted] to get all her treatment at the start but after that we could leave the room and get her food from the parent's kitchen. At the start of her treatment she wasn't really fit enough to go out the bedroom but after that, when she was fit, she could go out and about the ward or go to the playroom.

30. Soon after the rhinovirus outbreak though, we were put into isolation every time [redacted] got her chemotherapy. We were in isolation every other week throughout her treatment. [redacted] had seven rounds of rapid COJEC therapy. Each round lasted three or four days and in those three or four days [redacted] was really, really sick and really bad with the runs. She was just so unwell and she was getting nosebleeds because her haemoglobin and her platelets were dropping because she was so unwell.

31. After the chemo stopped, the next thing was that she needed blood transfusions and platelet transfusions because she was neutropenic. They had to get a dentist up to put a special light in her mouth to try and help ease the pain of all the ulcers she had.

32. Once this passed though, she was able to go out of her room. But sometimes during this period, I would open the door and there was this big bit of tape over the doorway telling us that we can't get out the room. A big white sheet went up on the door that said, "You're in isolation". If you didn't know at night, you woke up in the morning and you opened your blinds, and the tape and sign was there. [redacted] was two, going on three years old and when she saw the tape and sign, she would start screaming "I don't want to stay in the room, I don't want to stay in the room". Most of the time it was just because [redacted] had a

wee bit of diarrhoea which was really, really agitating. It was caused by the chemo.

33. I ended up fighting with my oncologist and infection control to say, “Look, you are putting [redacted] onto this chemotherapy, you know the chemotherapy is going to cause a lot of diarrhoea, a lot of sickness, so you should not be locking the child down, just because they’ve got a wee bit of diarrhoea”.

34. The doctors knew sickness and diarrhoea were side-effects of chemotherapy, but they still locked us down anyway. When I opened that door and [redacted], or any kid, saw that there was a sheet on the door, they automatically got really upset, because they knew that this is a sign that they couldn’t step out their room.

35. [redacted] was only two going on three, she was three when she passed away, but she knew what was going on. She could tell you the names of the meds that she needed, like you'd say to her, “Do you need paracetamol?”, and she would say, “No I need morphine, I'm really sore, Mummy”. The hospital was her life. She didn’t know about running about with kids, she didn’t know her ABCs, she knew nothing other than the hospital. She would see other kids walking about, she would watch the dinner trolley coming and she wanted to go and pick her dinner too. She couldn’t because there was this marker on our door and a line of tape that you aren’t allowed over. That was really hard for her.

36. It was really hard for me too. We all have to do hard things but when you get put into lockdown every other week, it’s physically and mentally draining. It really got to me because I was seeing my daughter hurting.

37. I just didn’t agree with that. I mean the doctors all knew all the side-effects of the medication they were giving her. So by lockdown, you'd have thought

they'd all agree and thought there's no point in isolating them, these meds are going to give them sickness and diarrhoea. It would be different if you went into hospital and you had sickness and diarrhoea, or whatever then yes, but not lock them up every time there's a stool that's a wee bit runny, because it wasn't fair on them. For [redacted] it was a side effect of her treatment.

38. [redacted] got the full seven rounds of rapid COJEC and in-between we did start to sometimes get out for a wee day visit. We were allowed out for two hours here and there. But she then was straight back in because she was due meds at certain times, so we'd need to get back in hospital for the time that her meds were due. Basically, for the first seven rounds of her chemotherapy, apart from a few, couple of hour's day releases, [redacted] was in ward 2A the whole time.

39. Once [redacted] had completed her rounds of rapid COJEC, I can't remember exactly when that was, they scanned her but they saw that the tumours still had a bit to go before they could operate. The gave her two rounds of TDD, which is a high dose chemotherapy, and it made her extremely unwell. I think this was at the end of August or beginning of September 2017. After the second round of the TDD, [redacted] was ready for surgery.

40. The hospital staff had her on a morphine pump, but she was still in real pain and they ended up giving her ketamine, which is something I still don't understand. I still don't understand why they would give a two-year-old ketamine. [redacted] was awake for 36 hours straight, she was hallucinating, and she was seeing things that weren't there. This was at the weekend so it was weekend staff.

41. The medical team, who do the pain relief, came in on the Monday and they were asking why the hell was this not sorted sooner. They were really angry.

[redacted] had a high pain threshold and in her notes it had said, go in higher with the morphine, and you've got more chance of getting her peaceful. But the weekend staff didn't, they went in with wee doses and worked it up, so it wasn't getting to the stage where it was hitting her pain. Then they added in the ketamine, which was just horrific, it was so bad. When that finished, that's when we got to go home for a wee overnight here and there, but it wasn't often.

42. Before her surgery in September 2017, we managed to get [redacted] away for a few days holiday. We went to the caravan for three days and then we went back into hospital to prepare her for surgery.

[redacted] surgery: Ward 3A RHC – September 2017

43. [redacted] surgery was on 24 September 2017, I think. It took place in ward 3C of the RHC. She was due to go to intensive care after her surgery, but [redacted] being

[redacted] she bounced back no matter what happened. The nurses called her "the miracle one". After this surgery, she should have been in an induced coma for two days. But straightaway after theatre, [redacted] woke up demanding Irn Bru and nippy crisps, which were salt and vinegar square crisps.

44. They did take her to PICU though as she was still quite tired. [redacted] never left my side. Parents are not allowed to stay in PICU, because of hygiene and stuff like that. But even if I went to the toilet, [redacted] was getting herself worked up. It got to the stage that the nurses were that scared she was going to burst her stitches. They gave me a recliner seat and a wee blanket so I could sit with her, because they were more concerned that she was going to damage herself with me leaving her. I was told I wasn't allowed to fall asleep, but eventually they just gave me a blanket and told me just to doze off if I needed to. Parents are not allowed to sleep and stay with children overnight in PICU.

45. [redacted] had surgery and 95 percent of the tumour was removed.

Treatment after surgery – stem cell transplant: Ward 2A and 2B RHC

46. The next plan was a stem cell transplant. [redacted] was in Room 1 in ward 2A of the RHC. She was to receive her own stems back, so they had to do a stem cell collection. A nurse came in from the Beatson hospital and they hooked

[redacted] up to a big machine. She had to just lie there for a few hours, while they took all these bloods. It was done over the space of three days, because they had to take quite a bit to try and get her platelets for the stem cell transfusion. They basically took her stem cells, filtered them through a machine, cleaned them and put them back into her. When that was done, we were told that there was a 95 per cent chance that it would be successful. They couldn't guarantee 100 per cent because there could have been a stem cell which had still had the neuroblastoma attached to it.

47. We moved forward a wee bit and then we went to stem cell transplant, but I can't remember the date for this. At that point [redacted] needed a high dose chemotherapy, which was the biggest dose she could get, so sort of an adult dose. This broke her blood down so there was nothing left in it, it was so she could get her transplant. When they did do this, [redacted] was severely unwell.

48. Transplant was one of the harshest times, because we weren't allowed to have visitors. The room [redacted] was in was in Ward 2A and it had double doors.

[redacted] had such a high dose of chemotherapy and she ended up really, really unwell. She had ice packs in her nose, she had platelets running, and she had blood pouring out her mouth. It was the worst I had seen her through the whole part of the treatment. [redacted] was discharged at the end of October 2017 as her transplant had been successful.

49. [redacted] then attended ward 2B RHC frequently as a day case attender during November 2017 and we started to talk about the Beatson for radiotherapy. We went there and they put her to sleep to get a mould made for her face so that her brain wouldn’t be affected by the radiation treatment she was going to get.

50. [redacted] developed a fever in November 2017 so we took her to the RHC. It was a line infection that [redacted] had, she was admitted to ward 2A and she was treated with antibiotics. I speak about this later on.

Amenities on ward 2A: March 2017 to January 2018

51. Ward 2A was set up for children with cancer. The parent kitchen was really, really useful because [redacted] was a fussy, fussy eater. I would make sure that my mum, or whoever, brought home cooked dinners, or I'd go and get her tins of macaroni, or wee things from Asda, so that I could heat them up in the microwave. The kitchen didn’t have a cooker but the microwave was really handy and we had our own fridge. Everybody shared the one kitchen, so if the wee one was sleeping or at surgery, you could go to the parents’ room, watch telly, or get something to eat. That was really good.

52. The other facility was that there was a big boat sized bath on the ward. It was at the very start of the corridor before you went through the double doors into where the rooms were. My [redacted] was obsessed with baths and she liked to use that.

53. There was a playroom, which had play leaders. The kids did all different things in there, like painting, games and stuff like that.

54. They also had tellies and computers that some of the kids could have and there were DVDs that you could take into the room. There was also Freeview on the telly with wee games. Obviously, [redacted] was a bit young to play with that sort of thing, but there were a good few things on the ward that the kids could use.

55. I also had the opportunity to speak to other parents in the parent's kitchen. I remember once going into the parent kitchen. I had got myself quite upset the first time [redacted] went for her scans and I remember one man approaching me, he was [redacted], and his [redacted] was in with cancer. He had totally lost his faith by this point and was really upset. He'd had enough by this point. He actually did the Humanist funeral for my daughter, because I did become very close with him and the family.

56. There were two other mums on the ward that I was really, really close with. At night time, if the kids were sleeping, we'd go into the parents' room, and we would sit with hot chocolate and cups of tea. We'd sit there for hours, just talking.

57. When that was taken away from us and when we were put into lockdown or isolation, I was stuck in the four walls. It was physically and mentally draining. I would then have to make video calls, and then have to console [redacted] for an hour, two hours at a time, because she couldn't see her gran, her auntie, her uncles and her cousins. She was really, really quite distraught with it, because her routine was that when she woke in the morning, she saw the doctors, and then her gran would come up. When that was taken away it was really hard on her; her wee routine had gone.

58. [redacted] room had her hospital bed and I had a pull-out bed from within the wall. It folded up and you would pull it down at night. [redacted] and I liked our home comforts, so we had our own quilt and pillows, which I just folded up and put

away, during the day. Other than that, we had the wee small telly and a shower room with a toilet. There was a TV in the room with Freeview channels, a wee seat next to her bed and a few other seats extra if anyone was visiting.

INFECTIONS – MARCH 2017 – JANUARY 2018

59. [redacted] had eight different central lines in ten months. Staff told me she had infections and if antibiotics didn't cure them then the line had to be changed. One of her lines had a hole in it and that's why that one was changed, but the other lines she had changed were all due to infections. They didn't really tell us much, they just said it was an infection and the antibiotics weren't treating it. Sometimes when [redacted] was on antibiotics, there would be two or three different antibiotics but her temperature would still be spiking and she was still really unwell. At the start, staff would sometimes tell me it could be tumour related, but when the tumours were gone, they said it could be the aftermath. The answers that were given were always little answers and what it maybe could be that was causing the infections.

60. On 22 November 2017 we had to take [redacted] to the RHC after she developed a fever. I took her to ward 2B, I had a phoned the ward to say that her temperature had reached 38 degrees. When she was an outpatient and she got a temperature above 38 degrees this is what the staff told us to do. The staff told us to go straight up to ward 2B. The staff told me that [redacted] had a line infection, but they also said she had pneumonia. The high temperature triggered a seizure and we were moved across to ward 2A. [redacted] was admitted as an in-patient.

61. First of all the nurses on ward 2A were trying to deal with the temperature and the seizure. The next minute, the room doors burst open, and I heard the alarms sounding. The nursing staff said that [redacted] room was going to get really

busy with the crash team coming up. They worked on her for 45 minutes, just pushing water into her and things like that. There was a doctor on the ward called Booboo, I don't know his real name, but [redacted] just absolutely adored him and that is what she called him. She'd wake up in the morning, put her lipstick and things on for him, it was just so adorable. After 45 minutes of being in this seizure, they turned round and asked her if Booboo could look at her and

[redacted] said, "Oh I've not got my lipstick on". The whole room burst out laughing at her coming out with this. After this I was again told it was a line infection she had. She didn't have a cough or anything, but they had her on oxygen for a few days after that incident. I have pictures of [redacted] when she was in this position showing all the monitors and tubes attached to her. It was quite bad.

62. I now know from the Case Note Review (CNR) that it was enterobacter cloacae and raoutella plantilcola that [redacted] had, but at the time all I knew then was that she was given antibiotics and that they removed her central line on 29 November 2017. Her antibiotics were stopped on 4 December 2017 and she was discharged home on 6 December 2017. No one told me what infection she had at the time, or how she got it.

63. It was really traumatic for [redacted] to get all these surgeries, and she needed two surgeries for each line removal and replacement. It was really very painful as well. Just a horrific situation. There was one occasion when [redacted] was getting her line put back in and she sat up as nobody was sitting with her. I got called to go down to her. When I went into theatre, there were doctors pressing on [redacted] face. I asked what was going on and they told me that [redacted] had ripped her line out. This angered me as someone should have had been watching her; the line is attached to the main artery in her body which could have caused serious damage. One of the doctors had the cheek to say to me that I'll need to bring her in a Babygro next time. She's three years of age, she doesn't

wear Babygros. Two days later, she went down again and when I came to get her, that same doctor had wrapped her up like a mummy. I was angry and [redacted] was getting more upset and worried that there was more going on as she had all these bandages around her. As she had ripped the line out, the nurses were pressing bandages into her trying to prevent the bleeding. It was quite harsh.

[redacted] relapse and palliative care: November 2017 – January 2018

64. Whilst [redacted] was in hospital to have scans done, on maybe the 25 and 26 November 2017. I was told at that time that her cancer was back and it had reached the brain.

65. I asked them what this meant and Dr Ronghe said he could ask for a trial for her but that he didn't think it would work. I wanted to try anyway so [redacted] started on the Beacon trial, which was two rounds of chemotherapy. After one round she took so unwell. I was told the cancer was spreading. Her bladder had stopped working and she had to be catheterised in theatre on 3 January 2018. But it wasn't just her bladder, the cancer was spreading down her spine and taking over every part of her body.

66. We were back in ward 2A by this time. [redacted] was crying a lot, with pain in her head. Dr Murphy, who was also based on ward 2A, said the best place to go to was neurology. We moved up to ward 3B or 3C in the RHC, I can't remember which. We spoke to the neurology team there and one of the neurologists said that he could put a stent in if that's what I wanted him to do. He said he couldn't say if he could get [redacted] off the operating table and through the operation, and that even if he did she was at a high risk of taking a serious infection like meningitis.

67. I said no to that because I'd been told she had weeks into months to live. We left the hospital on the 5 January 2018 and I took [redacted] home. The hospital staff had sorted us out with palliative care nurses who come into the house and they put pumps into both of [redacted] legs for all her medications to go into her.

68. We were at home when, on 8 January 2018, I said to the outreach nurse that I thought [redacted] had a bit of an infection. She wasn't eating or drinking. The nurse said that it was probably to do with the cancer and there was nothing we could do.

69. A couple of weeks before that I had signed a DNR order, it was called a Management Plan. Dr Murphy did it with me. The Management Plan said that I didn't want [redacted] ventilated, but it did say that she could be administered antibiotics at home. [redacted] wasn't given any antibiotics at home, and the outreach nurses didn't mention this either when I said I thought she had an infection.

[redacted] passed away at home on the [redacted].

70. Looking back I do find it quite upsetting that [redacted] wasn't given antibiotics at that time. We were told when we left the ward that she had weeks or months to live but in the end we only got [redacted] with her. I don't understand why she wasn't given them.

WATER: EVENTS INVOLVING WATER SYSTEMS

71. I didn't really know much about the problems with the water when I was in with

[redacted], but since I've watched the BBC 1 Disclosure programme and spoken to other parents. I now wonder if [redacted] infections were caused by the water. was only ever in the hospital and wasn't anywhere else to catch the infections in her lines. We barely left the hospital for months. [redacted] had a bath in the big bath in ward 2A every single night until we were stopped from using it in December 2017. [redacted] wasn't really fit enough to get a bath at this point though so I didn't question it and wasn't told any more about it.

72. The programme said that they knew about the water two years before the hospital opened and that they kept ignoring it and that if it hadn't been for the whistle-blower we still wouldn't know any of this. Hearing all this now, that makes me really angry and hurt.

73. You are still not able to use the water machines in the hospital. When I've had an appointment with my son, we were still not allowed to use the water machines. Three years on, surely they've sorted what's going on? If they had then the water machines would be back working, which none of them are within any ward or any corridor. To me this must mean that there is some sort of infection or something wrong with the water.

PREVENTATIVE MEDICATION

74. Towards the end of [redacted] treatment, she was given preventative antibiotics. She was given posaconazole, septrin and gentamicin. I wasn't given any information about these whatsoever. The doctors just said it was part of a new regime and that all the kids were getting them.

CLEANLINESS

75. After the rhinovirus outbreak in April 2017 we were always being moved rooms because they were doing deep-cleans. The nurses never told you why or anything, they just moved you.

76. At that time they brought in plastic drawers for the bathroom, and plastic drawers for the room; a wee set in both rooms. We had to put our stuff in there, we weren't allowed anything to be lying about the wards.

77. Towards the end of [redacted] treatment we were getting flung from room to room, while they did deep cleans in ward 2A. The nurses didn't tell us why but we were getting moved from one room to another room, and you were lucky if you stayed in a room for two nights before you were moved. When the rooms were being deep cleaned, there were big covers on all the doors in the rooms that were being cleaned so you couldn't see what was going on. I was walking past the rooms, sometimes with [redacted] in her pram and you do start to question, what is going on in there?

78. In the November and December 2017, it was industrial cleans they were doing. The ward was stinking of chemicals. They also started bringing in the cleaners twice a day at that time, whereas before it had only been once.

OVERALL IMPACT ON THE FAMILY

Overall impact on the witness

79. I watched the BBC Disclosures programme. I knew a few of the parents and it started with the kids from our ward and one of the children who had died. The hurt was there and the anger was coming. The more I was finding out, I was getting angrier and I was crying but it was sheer tears of anger. From the programme I was finding out about the water tanks; how long the water issues

had been going on for. Basically, if it wasn't for the whistle-blower who, basically put their neck on the line, we wouldn't have known any of this. The programme said that the hospital had been advised to change the taps on the ward in 2016, when all these babies were dying in Belfast, and they chose not to. I never knew anything about this, until it came on the telly.

80. The programme spoke to Jeane Freeman, and they asked if she thought they were cutting corners to save money, she said, "Oh no, I don't think that's what would have been done." I just wanted to jump through my telly and punch her in the face; she just looked as though she didn't have any care in the world, and look at what had happened. It looked like she didn't have any concern at all, for the parents that are sitting watching that, knowing their children went through it. It was really hurtful, and hard to watch.

81. Our children were put on antibiotics that weren't part of their treatment regime, so they could protect themselves. I found this out after [redacted] passed. The TV programme indicates that people knew about the water infections for two years before the hospital opened.

82. When [redacted] died I was told it was the cancer that killed her, but now after receiving the Case Note Review Report and watching the BBC Disclosures programme, I feel angry and hurt. I need answers. I have a lot of questions now.

83. After finding out all of this, there's just so many questions that hang over my head, and every day I wake up with a new one. I start to make myself physically ill with it all.

COMMUNICATION

84. [redacted] was included in the Independent Case Note Review and I was told this after she died. If you're in the ward, you're getting information. For the parents who are not at the hospital, if your child is involved with an incident at the hospital, even if it's ten years down the line, I feel that there should have been communication with me from the hospital. I had no communication with the hospital whatsoever. The hospital should have communicated with me about

[redacted] infection.

85. It was the Scottish Government who contacted me and even after I got the letter from them, the hospital still didn't communicate with me. I had no communication from the hospital. When I received the letter from the Case Note Review, it told me that if I wanted to question anything, I could contact them and I could have a meeting with the consultant or with them. I didn't see the point in a meeting; they weren't going to give me the answers I wanted. They asked if I wanted my consultant to have a copy of the letter but I think he already had it.

86. The Health Board's lack of candour could have hindered my right to pursue a civil claim on behalf of [redacted]. Prior to receiving the letter from the Scottish Government, I was unaware that the Hospital environment may have contributed to my daughter's death. I am now being advised of my rights on behalf of my daughter by my solicitors. I wish the Inquiry to be aware, that it was only through my own investigations and contacting a solicitor did I obtain the information I should have been given in 2018.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS/HEALTH BOARD

87. I didn't know about the Case Note Review (CNR) until I received a letter from the Scottish Government on 20 February 2020 telling me that [redacted] was going to be part of it. I just fell onto my seat and thought. "My daughter has been dead for two and a half years, how can you now hit me with this bit of paper saying that my daughter was one of the ones involved?"

88. After I received the notification that [redacted] was included CNR in February 2020, it completely shattered me; it absolutely shattered my life. It felt as though my daughter's life was worth nothing, for them to write that to me, it really, really angered me and upset me. I was already in a bad place at that point in time, so I really couldn't do anything about it. I had to get myself mentally and physically better for my children and that's why I only went to the lawyer this year, when I felt I could.

89. It was totally shocking and horrifying to read that your daughter's case notes were being reviewed after all that time. For them to send a letter saying

[redacted] was a major case but that they're taking no blame once again. How can you take no blame when it's there in black and white? It was so hurtful. It came across as if they were saying, your child is dead, what do you want us to do? That's how it came across to a parent.

90. I haven't been through all the main CNR report. Unless you are a doctor or a specialist, you're not going to understand it. We don't know what we're looking for or what we're not looking for. There's a lot of pages with percentages and names on them so a lot of that, I didn't understand.

91. In April 2021 I received [redacted] individual report from the CNR. I found out that in November 2017 [redacted] had enterobacter cloacae and raoutella plantilcola.

92. When I read the report it said, [redacted] had this infection, she had that infection. The report said it could've been a contaminated line, but the review can't say for definite that was what happened. At the bottom of the report they say how severe the infection that [redacted] had was. That was quite hard to read because the report said it was a really serious infection; it was a major one. The hospital did take it seriously at the time, because they ended up having the crash team called to help her. The report conclude that they didn't really think that the hospital had anything to do with it. At the end of the day, I think there is a lot more information that shows otherwise. At first we didn't know anything about the issues with the hospital, and then this documentary came out and it gave everybody a new insight. The information in the documentary was provided by people that worked there; it's been specialists, the water level was never right from day dot.

93. It was just so hurtful, it's like the hospital didn't care about my child. That's how it came across to me and the more I watched the TV programme, the more I thought the infection was more dangerous than cancer itself. It made me think that if [redacted] did have that infection in her line, is that what killed her quicker? It made me wonder if the infection in her line was fighting off the chemo and preventing it from working and maybe that's why she relapsed. I remember getting so upset that day, I phoned the Legal Aspects team at the hospital and I demanded her medical notes. The woman I spoke to said I was not the first to be on the phone today.

94. Once I felt better I ordered [redacted] medical notes and I went to see Stephanie Young at Thompsons. I was angry that the DNR order I had signed said that I didn't want her to be resuscitated but that antibiotics could be given. I was

angry that the outreach nurse who was there when [redacted] was in palliative care at home, hadn't offered them at all.

95. I wasn't in the right place emotionally at the time when [redacted] was dying to remember that I had said she could get antibiotics but surely the medical team in charge of her care should have known this? I remember them saying they weren't going to take any bloods but I knew that. My daughter was lying there, severely unwell so I'm not going to think "Wait a minute, you can give her antibiotics". I didn't know any of this until I went to look at the DNR order I feel let down in this aspect as well.

96. [redacted] DNR order is also not in her medical notes, amongst a lot of other information that's missing too. I had lots of conversations with doctors and consultants so there should be plenty of notes in her medical notes but they're not there. The copy I have given you is my copy, the hospital copy is not in her notes.

97. I am still a member of various groups on Facebook groups run by the parents and I hear a lot of information from there and through that I hear from parents that are still on the ward.

CONCLUDING COMMENTS

98. The staff and doctors were amazing, I can't fault them in any way. The only thing is that maybe they knew what was going on with the building and didn't tell us. Whether that was to prevent upset on the ward, or to prevent something else, I don't know; there must've been a reason. But I can't fault the staff in any way, they were amazing with [redacted]: from the play team, right up

to her consultants, and her nurses, they were all absolutely fantastic with her. I can't fault any of them whatsoever.

99. I just feel there is blame there and someone needs to accept that the blame is on them. The CNR letter I got didn’t even have a thousand words on it and I just feel my daughter’s ten months in hospital is worth more than what this was saying to me. It’s disgusting, it’s just so bad.

100. Shortly after [redacted] passed away, wards 2A and 2B were shut down and moved to ward 6A QEUH and ward 4C QEUH for transplant. I’ve got two other kids so I’m in and out of the hospital and I’ve seen that the ward is still lying ripped apart. There’re still bits of the roof hanging down and bits of the wall are off. Why is it still shut after three years? I think there’s something more to it that they aren’t telling us and it’s answers we deserve.

101. I just feel as though I've been let down in every way. If I take the boys in to the hospital now I start getting anxiety and I start really being unsteady about going in. I just feel as though I can't trust the hospital. Why did we not know about any of this, why was I not told [redacted] had this infection, because clearly they knew. They knew [redacted] had this.

102. I will now question everything. If I take my son up to the hospital when he’s not well, I'm going to keep questioning the staff; I'm not going to let anything lie unturned and I’m not going to let them push me away. Right now, I just feel totally and utterly disgusted. I feel so let down by the NHS and also the trust with them has completely gone.

103. I believe that the facts stated in this witness statement are true, that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

APPENDIX 1 – TIMELINE (LC/01)

- Early March 2017: [redacted] had a number of admissions to RHC where Louise was told [redacted] had some sort of viral infection and was then discharged.
- 12th March 2017: [redacted] was admitted to RHC for a couple of days for the same issue (viral infection) and was discharged. Louise was told [redacted] haemoglobin level was low, which is what happens with a viral infection.
- 16th March 2017: [redacted] is admitted to ward 2C of RHC after being examined in the CDU (clinical decisions unit).
- 17th March 2017: around one or two in the morning, [redacted] was taken for an X-ray and CT scan as they'd found something in her blood. The scans revealed that [redacted] liver looked enlarged, and that she had few pockets of blood on her brain. Later that morning [redacted] was taken for an ultrasound and two masses in

  [redacted] stomach were found. [redacted] platelets and haemoglobin levels were also seen to be extremely low. [redacted] is moved to ward 2A following the discovery of the two masses in her stomach.
- 18th March 2017: [redacted] condition deteriorates, and she is given a platelet transfusion, a blood transfusion and is placed on a morphine pump for the pain.
- 20th March 2017: [redacted] is given a DMSA scan, an MRI scan and has a bone marrow aspiration done at the request of her consultant Dr Ronghe. [redacted] also had a biopsy taken of her tumour that day so that it could be sent for analysis at Great Ormond Street Hospital. 4-6 weeks later the results of the biopsy showed that [redacted] had very rare N-MYC gene tumour.

- Sometime during the first week of her admission, [redacted] has surgery to put a central line in.

- 23rd March 2017: [redacted] is given an initial diagnosis of stage four high-risk neuroblastoma cancer by Dr Ronghe and begins the first of seven rounds of rapid COJEC chemotherapy at the advice of Dr Ronghe.

- 26th March 2017: around the 26th March [redacted] had her first central line infection. [redacted] had a high temperature and wasn't eating or drinking. Staff did not say what the infection was but said it could be chemo related or could be coming from the tumours. [redacted] was given antibiotics, but these did not work.

  [redacted] was then taken to surgery to have her central line removed.

- 27th March 2017: sometime in the week beginning 27th March, [redacted] official diagnosis of high-risk stage 4 neuroblastoma cancer is confirmed.

- 28th March 2017: [redacted] has her second central line fitted.

- April 2017: sometime in April 2017, ward 2A is shut down due to a rhinovirus outbreak. Louise and [redacted] are confined to her room, were not allowed visitors and not allowed to use the parents' kitchen. Immediately after the lockdown, infection control and health and safety staff asked that all personal possessions be removed from [redacted] room. Shortly after the lockdown, Louise and [redacted] began being moved to different rooms around ward 2A. Nurses often said that this was so people could be closer to something or because some rooms needed to be deep cleaned.

- August/September 2017: around August or September [redacted] completed her seven rounds of rapid COJEC chemotherapy. Scans showed that her tumours still had some way to go before she could be operated on. [redacted] then began two rounds of TDD high dose chemotherapy.

- 24th September 2017: [redacted] had surgery in ward 3C of RHC to remove her tumour, 95% of the tumour was removed. [redacted] was moved to PICU after the surgery.

- Shortly after the surgery, [redacted] went through a stem cell collection in preparation for a stem cell transplant.

- Sometime after the stem cell collection, [redacted] had a high dose of chemotherapy and then received her stem cell transplant shortly after that.

- October 2017: at the end of October, [redacted] was discharged after her stem cell transplant was found to be successful.

- November 2017: [redacted] attended ward 2B RHC frequently as a day case during November and discussions were had about [redacted] having radiotherapy at the Beatson Centre.

- November 2017: sometime later in November, [redacted] developed a fever and was admitted to ward 2A RHC. [redacted] was found to have a line infection and was treated with antibiotics.

- 22nd November 2017: [redacted] is admitted to ward 2B RHC with a line infection and pneumonia. Her high temperature triggered a seizure and [redacted] was moved to ward 2A where she was admitted as an in-patient. A crash team was sent to ward 2A to deal with [redacted] temperature and seizure. [redacted] was put on oxygen for a few days after the seizure and treated with antibiotics.

- 22nd November 2017 – [redacted] is diagnosed with Enterobacter Coloacae and raoutella plantilcola. Infection was identified in the case note review and Louise was not told at the time.

- 25th/26th November 2017: around the 25th or 26th November, [redacted] had a number of scans that showed her cancer had returned and it had reached her brain. Dr Ronghe suggested a trial treatment called the Beacon trial which involved two rounds of chemotherapy.

- After the first round of chemotherapy on the trial, Louise was told that the cancer was spreading down [redacted] spine to the rest of her body. [redacted] was then moved to neurology in either ward 3B or 3C RHC.

- One of the neurologist suggested an operation to put a stent in, but couldn't guarantee that [redacted] would survive the operation or go through it without another serious infection such as meningitis. Louise refused this operation.

- 29th November 2017: [redacted] central line is removed.

- 4th December 2017: Antibiotics are stopped.

- 6th December 2017: [redacted] is discharged.

- 1st January 2018: around the first of January, [redacted] had become unwell and was complaining of a sore stomach. She was admitted into to the RHC, though Louise could recall which ward. Initially the doctors thought it could be an issue with her gut and so she received antibiotics. When these failed to have effect, further investigations found that her bladder was no longer functioning.

- 3rd January 2018: [redacted] is taken to theatre to have a catheter fitted.

- 5th January 2018: [redacted] is discharged and taken home.

- 1st – [redacted] : [redacted] is in palliative care.

- 8th January 2018: During her time in palliative care [redacted] developed symptoms of having a line infection. As Louise was so familiar with line infections at this point, she immediately picked up on the signs that something was wrong. She asked the nurses to test [redacted] for a line infection and was told that they did not test children in palliative care for infections, they could only make her comfortable. Therefore, Louise is unable to establish the name of the infection. Later on, when reviewing [redacted] management plan she noticed that it said that [redacted] was to receive antibiotics if she spiked a temperature. Upon reviewing the medical records, we have been unable to establish a clear timeline of events that occurred in [redacted] final days due to only partial records being provided to Louise.
- [redacted] – [redacted] passes away at home.