

Scottish Hospitals Inquiry

Witness Statement of

Leann Young

WITNESS DETAILS

1. My name is Leann Young. I was born on [REDACTED]. I am [REDACTED] years old. I am [REDACTED].
2. I am the mother of [REDACTED] [REDACTED]. [REDACTED]'s date of birth is [REDACTED]. He is 9 years old.
3. I live with [REDACTED] in [REDACTED].

OVERVIEW

4. My son is [REDACTED] [REDACTED]. [REDACTED] was diagnosed Burkitt Lymphoma, Stage 4, in April 2018. [REDACTED] had just turned 6 years old a few days before he was diagnosed. He was admitted on 12 April 2018, and was an in-patient until October 2018. He had the odd day out but was an in-patient for the majority of this time. [REDACTED] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between April 2018 and February 2019 when he finished his treatment. He attended both hospitals as an in-patient and as an out-patient for nearly a year. [REDACTED] still attends appointments every 6 months to see his oncology consultant, Dr Chaudhury. At these appointments he gets a blood test to make sure everything is fine with his blood. He is also attending community physiotherapy every three to four weeks to try and increase the muscle strength in his legs. [REDACTED] also received care from Child and Adolescent Mental Health Services (CAMHS) although he has now been discharged.

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5. [REDACTED] spent the majority of his time in wards 2A and 2B of the RHC which are known as the Schiehallion Unit. When we were first admitted, ward 2A was fine. Staff were really supportive but the longer we stayed, the more we noticed things that were going on. The nurses, for example, were having to take on more work, for example getting diluting juice for a patient and changing bedding. Following the closure of the Schiehallion Unit in 2018, [REDACTED] was treated on wards 6A and 6B in the QEUH. This was supposed to be the 'new' Schiehallion Unit. I stayed with [REDACTED] for the duration of his admission. My mother helped out and came to the hospital with us. She had a room at the CLIC Sargent facility. I can speak to the experience which [REDACTED] and I had on these wards.
6. With the assistance of my solicitors, I have prepared and provided the Inquiry with a timeline showing the dates on which [REDACTED] attended hospital and the wards where he was treated. The timeline is attached to this statement as an appendix (LY/01) and I confirm that it is accurate to the best of my recollection.
7. There are some specific events that I would like to mention. [REDACTED] contracted aspergillus and other infections during his admission. Due to this, he was kept in 'source isolation', where he was not allowed out of the room. He was not able to play or speak with other children on the ward. He was prescribed prophylactic antibiotics in 2018 which I think may have been connected to the issues with the water supply. We were moved rooms quite a lot which had an impact on [REDACTED] and the treatment he received on other wards. There were ongoing construction works at the hospital during [REDACTED]'s time there, which in my view, may have impacted his experience. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

8. I stay on my own with [REDACTED] in [REDACTED] .

9. [REDACTED] is in primary [REDACTED] and goes into primary [REDACTED] after the summer. He was in primary [REDACTED] when he was first admitted to hospital. [REDACTED] was quite a happy, healthy little boy before he went into hospital. He doesn't have any siblings so was pleased when his school friends came to visit him. His friends were prevented by the hospital from visiting him after the 18 May, which I discuss further below.
10. [REDACTED] is quite a popular little boy within his class although it tends to be mainly the girls that flock around him. He's quite a shy boy but is very talkative at home. He's not one for being the leader and prefers to take a step back. He loves his computer games, his IPad and his X-box, as many 9 year old kids do. He would rather sit in and play on his IPad than go outside. He is quite reluctant to go outside sometimes but I don't know if this because of everything he's been through. He has not really mixed with children his own age. He was only in primary [REDACTED] when he was diagnosed so he has not had a lot of time with children his own age and he's an only child. He does like to stay in the house with me. He has separation anxiety too. As a family, he loves going away in my mum and dad's motorhome. We try to go away in it as much as we can. He just loves being away and using the kayak my parents have or going out on his bike. I did not think we would get to see him out on his bike again because he has lost some strength in his legs but last summer he called me outside to see him riding his friend's bike which was really nice to see.

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

Admission to hospital: April 2018

11. [REDACTED] was diagnosed with Stage 4 Burkitt Lymphoma Leukaemia on 18 April 2018, when he was 6 years old. [REDACTED] had been complaining of a sore head and saying that things were upside down. He was also complaining about having a sore tooth, so on 9 April 2018, I took [REDACTED] to the dentist. He had an abscess which needed to be removed. On 10 April 2018, [REDACTED] still had a

temperature so I took him to the GP. I was told it was an ear infection and given antibiotics for him. By 12 April 2018, [REDACTED] was screaming in pain so we got an emergency appointment with the GP and I took a urine sample with me. Later that evening, I had to call NHS 24 and take [REDACTED] to the out of hours clinic in Paisley. They asked for him to be taken to QEUH Children's Hospital for further investigation. We attended the Accident and Emergency department initially, then [REDACTED] was given a bed in the Clinical Decision Unit (CDU) while more tests were carried out. He was then admitted to ward 2C (Acute Receiving Unit) while we waited for the results.

12. During this time, [REDACTED] had raised Lactate Dehydrogenase (LDH) levels in his blood. When we were told he had raised LDH levels, I questioned it with the doctors and they explained it to me using all sorts of medical terms I didn't understand as a parent. I googled it and the word cancer came up. At the time, I didn't understand what it was or what the implications could be. The Haematologist advised that a bone marrow biopsy would be carried out. Initially doctors were carrying out the biopsy as they thought [REDACTED] had an infection and they wanted to determine what kind of infection it was and what the right course of treatment would be but when the results came back they showed abnormal cells. Urgent blood tests were carried out and we were moved into ward 2A, room 16 on 17 April 2018.
13. The following day, 18 April 2018, [REDACTED] was given a formal diagnosis of stage 4 Burkitt Lymphoma Leukaemia. I was told that the cancer was around his brain and Central Nervous System (CNS).
14. During [REDACTED]'s overall admission, he had 6 rounds of chemotherapy which included two rounds of maintenance chemotherapy at the end. He also had multiple bone marrow biopsies carried out during his treatment to check his progress.
15. [REDACTED] was violently sick with the chemotherapy and was on anti-sickness medication. His chemotherapy wasn't delayed due to the sickness but it did

mean he had to have Total Parenteral Nutrition (TPN) which gave him all the vitamins and nutrients his body needed. It was given to him through his Hickman Line. He also had a number of infections during his admission.

Experience on Ward 2A: April 2018 – September 2018

16. [REDACTED] was admitted to ward 2A in April 2018. He had a Hickman Line fitted on 20 April 2018 under general anaesthetic. His line was fitted on his right side, just above his nipple via a cut in his neck. I believe the line goes into the main artery but I'm not entirely sure. He then had a bone marrow biopsy before he started his first block of chemotherapy.
17. I was given a copy of [REDACTED]'s treatment plan at the start of his treatment which included a list of all his chemotherapy drugs that he was to have. At the start of each block, the consultant would come in and go over that specific section of the treatment.
18. When [REDACTED] was first admitted, he was absolutely terrified of anyone coming in his room. It didn't matter if it was a doctor, a nurse, the kitchen lady or cleaners. It didn't matter who they were, as soon as anyone came in he would scream and cry. It got to the point where I had to put a note on his door saying, "When you come in the room, please say who you are and why you're coming in" so it gave him peace of mind. He was terrified as he'd been poked, prodded and had blood tests done and he was just scared as to what they would do next.
19. We started off in room 16 and there were no issues there. We were moved to room 9, I think because they had someone new coming into the ward.
20. On 15 May 2018, [REDACTED] was being sick. He had VRE which is vancomycin-resistant enterococcus. I understand this is an environmental bug.
[REDACTED] often had VRE. When he had VRE, he was moved into source isolation.

21. On 18 May 2018, we were in room 9. I recall there were people in pouring chemicals down the drains. A nurse told me that they had to pour a chemical down the toilet and shower. No reason was given as to why this was.
22. On 1 June 2018, [REDACTED]'s infection markers were raised. I was told that he had a fungal infection but I was not told the name of it. [REDACTED] was put on medication to treat the infection. This delayed his chemotherapy treatment by 10 days. I have only recently discovered, after reviewing [REDACTED]'s medical records, that the infection was aspergillus fumigatus.
23. On 5 June 2018, we were moved from room 9 to a room with double door entry. I think this was a VAC room because it had double doors. We were only told about this move at the last minute. These were the rooms that children who had bone marrow transplants would go into. They had a sink just as you came in the double doors for the doctors and nurses before they came in the patient room. We were told that the room we had been in needed to be cleaned.
24. I think it was also on 5 June 2018 that we were told that all children who had central lines were going to receive Ciprofloxacin as a precautionary measure. I was not told why.
25. On around 6 June 2018, we were told we would be moving rooms again in the morning but we didn't move until 10 pm that night. We were only allowed to take toiletries, clothes and [REDACTED]'s cuddly toy that he slept with. We had to leave the rest of our belongings, gifts [REDACTED] had received and toys from the charities with no explanation other than being told we'll get the items back once they've all been through the cleaning regime. The room we had been in was sealed off with a plastic covering. A mist was blown into it which I was told was a cleaning agent. We were moved to a much smaller room. It may have been room 14 or 15.
26. I recall that around this time, we were told that the pipes behind the sinks in the rooms were to be changed because children were getting infections from

the water. I think we were told that bugs were sticking to plastic in the pipes. I cannot remember if we had to move rooms while this work took place or if we only had to leave the room for a short while.

27. [REDACTED] was put back into source isolation on 7 June 2018 because he had VRE again. [REDACTED] was put into source isolation quite a lot. There were occasions when they took stool samples from [REDACTED] to test and see what was going on. Around May 2018 there was a whole period of two weeks where the stool samples went missing. I cannot recall exactly when it was but I remember there was no sign of them being sent away and no sign of results. We don't know what happened to them so for those two weeks, [REDACTED] could have been allowed out of source if we knew what it was he had but because those results had gone missing, he spent time in isolation which he might have avoided.
28. Being in source isolation is difficult. For example, I could not go to the parent kitchen myself to get [REDACTED] what he wanted to eat or drink. The hospital food was horrendous. It was all dry and not what you would want to give to a child who was fighting cancer. At one point, [REDACTED] had not eaten anything for the best part of two weeks due to being unwell. One day out of the blue he asked me for a drink of milk. I wasn't able to get it myself in the parent's kitchen due to us being in source so I had to ask the nurses. By the time we got it though, which was hours later, the notion had worn off. If a child hasn't eaten and they take a notion for something, they should be able to get it when they need it.
29. On 10 June 2018, blisters appeared on [REDACTED]'s body. He was given acyclovir intravenously because doctors thought he had chicken pox. He'd already had chicken pox the year before. We were still on the ward at this time and they took a swab from one of the spots on [REDACTED]. I was told that if the swab was positive, [REDACTED] would have to be moved off the ward due to the infection risk to other patients. I was told the swab came back negative for chicken pox and [REDACTED] was taken off the medication.

30. A couple of days later, on 14 June 2018, Dr Chaudhury came to tell me that a mistake had been made and that [REDACTED] did have chicken pox. She said that the other doctor had looked at results on the same day but a different month. [REDACTED] wasn't started back on the medication as it was too late to put him back on it. He shouldn't have been kept on the ward. Dr Chaudhury apologised for this error.
31. On 17 June 2018, [REDACTED] started his third round of chemotherapy,
32. On 6 July 2018, [REDACTED] was given two doses of his anti-sickness medication. He had been given permission to attend a wedding that day. He had one at tea time and he was given an extra one later as the previous one hadn't been signed off in his notes. I think there had been a change from the night shift. He received too much anti-sickness medication. This meant that [REDACTED] could not have anti-sickness medication for a long time, as the levels of anti-sickness medication in his system were still too high. He was violently sick and could not have medication to help him. There are two nurses who come in to administer medication so one of them should have noted it or at least noticed it hadn't been recorded. My mother [REDACTED] put in a verbal complaint about this but I heard no more about it.
33. I learned how to administer his medication. The nurses taught me how to give [REDACTED] medication through his NG tube, which is the tube that ran from his nose into the gut. Sometimes this came out when he was sick and he had to be pinned down to have it reinserted if he wasn't due to go to theatre. This was quite traumatic for [REDACTED]. Me giving him his medication through his NG tube was easier and less stressful for [REDACTED] because he was quite terrified of people coming in his room at first. I was able to see the doses drawn up for him too. The nurses were there during the night and later on in the evening to give him his medication though.

34. On 11 July 2018, [REDACTED] had to have five teeth removed. The chemotherapy that the children are on can cause mucositis. This can cause a breakdown of their mouth, through their gut and out the other end. [REDACTED] had a couple of holes in his teeth which presented an infection risk. The best thing to do was to remove his teeth. This was because his neutrophils, a component in the blood, were so low. This meant he was at a higher risk of infection. If his neutrophils were below one then his immune system was at risk if he didn't have any protection to fight off infection. Usually his blood would recover itself in a few days or weeks but on the odd occasion, if quite a bit of time had gone past and his blood hadn't recovered, he would be given a medication that would help boost the neutrophils to bring them up to a suitable level. This was to help fight off infections. Neutrophils also had to be above a certain level for chemotherapy too.
35. [REDACTED] had his teeth removed under general anaesthetic in theatre. I think we moved rooms but can't remember exactly. I do remember we had been in a room with double doors before [REDACTED] had his teeth extracted, but I think we were in a room with a single door afterwards. I remember writing a note and sticking it to the door, which was a single door, after his teeth had been removed. [REDACTED] had been worrying the Tooth Fairy wouldn't know where he was. I wrote a letter and stuck it to outside of his room. The nurses wrote back to him which helped build his spirit a wee bit.
36. On 21 July 2018, [REDACTED] had a temperature spike of over 40 degrees. It took hours before he was given calpol to help bring it down. I think the nurses were too busy with other things to get to him. He was in ward 2C.
37. On 13 August 2018, workmen appeared first thing in the morning to remove cladding from the building. They were outside [REDACTED]'s bedroom window. I recall this work went on for weeks. During that time, there was scaffolding up around the children's hospital.
38. On 16 August 2018, [REDACTED] started his 5th round of chemotherapy. On 26 August 2018 he was put into source again with VRE.

39. On 31 August 2018, [REDACTED] was told that his cancer was in remission. He still had a further round of maintenance chemotherapy to go through in September. [REDACTED] had his final round of chemotherapy in ward 2A on 12 September 2018. He was discharged to the CLIC Sargent House to keep him close to the hospital because his blood counts would often crash after chemo. We lived too far away from the hospital to be able to get [REDACTED] there quickly. He needed to be near the hospital.

Closure of Ward 2A and the move to the adult hospital: late 2018

40. On 18 September 2018, we were at CLIC Sargent House and we saw on the news that the Schiehallion Ward was closing. I had been in the RHC the day before and there was no indication the move was happening. [REDACTED] was due to go back over to ward 2B in the RHC for a blood test the next day so I phoned the ward to make sure I knew where we were to go.
41. The nurse had not seen the news and knew nothing about the closure! You'd think the people working there would at least have had an idea.
42. On 20 September 2018, I was given a letter telling us the ward was closing and moving to ward 6A in the adult hospital. The letter did not say why. I do not have a copy of it now.
43. [REDACTED] was an inpatient on ward 2A on 25 September 2018, having spiked a temperature. This was the day before the move to the QEUH happened on 26 September 2018. It was organised chaos: there were no additional staff to help. Nurses were looking after everyone and everything. They were packing up everything in all the different rooms, all the equipment, medication and furniture. [REDACTED] had to wear a mask on his face. Once we moved over to 6A, they then had to unpack everything. This impacted how they were able to deliver care as you never really saw the nurses in the rooms at this point. Children are supposed to have their observations taken

every 4 hours but the nurses were just so busy with the unpacking and moving that the student nurses would get put in to do the observations.

44. If the observations weren't taken every four hours and he had a temperature, would have to go with-out calpol to help get his temperature down. If he was continuing to get temperatures when he was already on antibiotics then it might be a sign that another infection was growing. Staff were supposed to take blood cultures and send them off so if the antibiotics he was initially put on to fight the infection were the wrong ones, if the blood cultures weren't done, then time had been wasted on the wrong antibiotics.

Experience in the QEUH (adult hospital): late 2018 – 2020

45. In ward 6A, there was no playroom. When [REDACTED] wasn't in source on 2A, he was able to use the play room but there were no facilities like that on 6A. The play leaders tried to bring activities and toys in but they didn't have the storage for everything they had on ward 2A so they had to go back and forth for things, which meant taking them away from other patients if a child wanted something. There were no facilities for [REDACTED] to utilise on ward 6A.
46. We didn't have a parents' kitchen on ward 6A either. There was nowhere to store food, make a coffee or even sit and have a chat with other parents, get their support or even just have a cry.
47. [REDACTED] was allowed to go home to the CLIC Sargent house on 12 October 2018. On 19 October 2018, [REDACTED] had to go to ward 6A, from CLIC Sargent, to get his line cleaned and bloods checked. His line was cleaned weekly. The dressing is removed and they use a roller top type bottle with alcohol to clean round it. It was then dried off and a new dressing was put over it. There were a couple of times where it looked red and crusty round about it but it wasn't swabbed. They just used a foam pad that would go between the dressing and [REDACTED]'s skin to keep it clean.

48. To get to ward 6A, [REDACTED] had to use the lift in the adult hospital going up to the ward. They did not have a dedicated lift for the children at this time which was quite a concern for me. Previously, you could walk through a long corridor from the RHC and go up to the adult hospital that way but we were advised not to use the children's entrance due to the cladding being replaced. We were asked to use the entrance at the adult side of the hospital where people would stand outside smoking. Our children were at a higher risk of infection and we didn't know who had been in the lifts, what they were there for, why they were there. There were a lot of visitors using the lifts to visit other patients. Patients themselves were using the lifts after having been out to the shops. [REDACTED] would be sat in his wheelchair in the lift, which was jam packed with people who were leaning over the top of him or had their hands in his face. I was concerned that he had to do that initially to get up to the ward and then, once there, we had to go through ward 6A to get to Day Care. Not only that, [REDACTED] could have brought something in to ward 6A when he was trying to get to Day Care. It could put him and other children at risk.
49. [REDACTED]'s central line was removed on 14 November 2018. He'd finished his treatment but his blood counts hadn't recovered. Even when he was able to ring the bell on 19 October 2018, when he'd finished his treatment, we still couldn't go home due to his blood counts being so low. This is a bell that children with cancer ring to celebrate and mark the end of their treatment. We had to be within an hour of the hospital in case [REDACTED]'s bloods crashed but because we stayed an hour and half away, we were discharged to CLIC Sargent House.
50. Once [REDACTED]'s treatment had finished, he had to attend Day Care once a week to get the lines flushed to make sure they were still functional and didn't clog up.
51. After [REDACTED]'s treatment had ended, there were a few times where he had to be admitted as an in-patient. Quite often, there would be no space on ward

6A, so he could be put elsewhere within the RHC. I don't know if this was because every room was full but we weren't told otherwise.

Other Admissions: End of 2018 – February 2019

52. On 10 December 2018, [REDACTED] had Respiratory Syncytial Virus (RSV). He was admitted for three or four days and put on antibiotics and fluids. I think it was ward 3 in the RHC this time as there was no room in ward 6A.
53. [REDACTED] was diagnosed with shingles on 6 January 2019 and was admitted to ward 2C in the RHC, which I believe is a general ward. He was put on acyclovir and was supposed to be in there for about 2 weeks.
54. On 18 January 2018, I saw the story about the pigeon droppings. As we were not on our "home ward", it took several hours for me to find a member of staff who could talk to me about it. When a nurse did come, I asked her if [REDACTED] was at higher risk because of it. The nurse's response was that [REDACTED] could go home that day. She did not answer the question.
55. [REDACTED] spiked a temperature on 10 February 2019. He was admitted to another ward in the RHC, ward 2C I think, as there was no room for him on 6A. He was diagnosed with flu and given fluids. He was discharged a few days later.
56. When he was on a different ward, it was difficult to get hold of staff from the Schiehallion ward as they see all their patients first then go round the wards where their other patients are.
57. [REDACTED] continues to have check-ups every six months.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water Incidents in RHC 2018

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58. There were filters on the taps and shower which were there during our admission. These would be changed every so often during our time there. The sink in the room was only for hand washing.
59. To my mind, the fact there were filters on the taps and the showers indicated there was a problem with the water which impacted on patient safety.
60. On around the 18 May 2018, I was told by the nurse that they had to pour a chemical down the shower and toilet of the room [REDACTED] was in. We weren't told why, just that we couldn't use the shower for a while to allow the chemical to go through the system.
61. On around about 6 June 2018, I was told by another parent that the hospital were going to change the pipes behind the sinks in the room because children were getting water infections from bugs that were sticking to the plastic in the pipes. I can't remember if we had to leave the room for a time or whether we moved rooms. Their child had an infection because of these bugs.

Water: communication

62. We were told the sink in the room was not for drinking water. It was only for hand washing but we were not told not to use the bathroom water for brushing our teeth. We were told by nurses it was fine to use.
63. I asked the nurses why there were filters on the taps but I was just told it was part of the hospital protocol and that they were always on the taps. I wasn't told the reason why.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and impact

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64. [REDACTED] was put into source on 15 May 2018 because he was being sick and had VRE. Being placed in source was pretty constant during his duration at the hospital.
65. [REDACTED] would be in source isolation for 2 or 3 weeks then the VRE would clear for a few days but he'd be back in source isolation again. It continued like this during his stay.
66. Sickness can be a side effect of chemo but his diarrhoea, I'm not so sure. As far as I'm aware from looking up VRE, it's classed as a hospital super bug and is passed on by touch. [REDACTED] hadn't been allowed out of his ward or room and we weren't going anywhere so the infection had to have come from somewhere. I was quite on top of the cleaning including the touch points in his room, light switches, monitors with antibacterial wipes. I'd clean them, 3, 4 or 5 times a day to try to minimise the risk but the infection was coming in from somewhere.
67. On 1 June 2018, [REDACTED]'s infection markers were raised. Staff were quite baffled as to what the infection was and where it was so they carried out quite a lot of tests on [REDACTED] including a CT scan and ultrasound scan. He had his eyes examined too as they wanted to see if the infection was at the back of his eyes. They diagnosed a fungal infection.
68. [REDACTED] was already on antifungal antibiotics but when they diagnosed him with the fungal infection, his dosage was increased and he was given it daily. He was already being really sick because of the chemotherapy and the antibiotics added to this. The antibiotic he was on was called Ambisome.
69. [REDACTED] was back in source on 7 June 2018, once again with VRE. I can't remember how long for. All the occasions with VRE seem to merge together.

70. ██████'s chemotherapy was delayed by 10 days due to the fungal infection he contracted.

HAIs: communication

71. I asked the nurses who were coming in and out doing ██████'s observations, what ██████ had. They would just keep saying, "Oh, we'll go and check his results" or "We'll check what's on the system", then they would disappear off. Eventually someone would come back, but it wasn't clear information they would come back with.
72. It was the nurse in charge who told me ██████ had VRE. She handed me a wee slip just explaining what VRE was. ██████ wasn't put on any treatment for it as it's resistant to antibiotics. It was just something he had to ride out until the symptoms cleared up.
73. We were never told he was clear of VRE. His symptoms would just clear slightly and they would allow him to come out of source isolation. We were never actually told it was gone only that when he developed further symptoms it was back again.
74. I wasn't told the name of the fungal infection he had in June 2018, I found out from his medical records that it was aspergillus fumigatus.

PREVENTATIVE MEDICATION

Preventative medication

75. ██████ was put on prophylactic antibiotics three times a week as part of his treatment protocol. These were environmental antibiotics he was given them three times a week, Monday, Wednesday and Friday. At the time we believed it was part of his treatment plan. No one explained it as being anything otherwise. On 5 June 2018, I was told we were moving rooms. On

that day Dr Albert came in and told us that all the children on the ward with a central line were getting put on Ciprofloxacin. I wasn't told why though.

76. [REDACTED] was put on ciprofloxacin but it had to be changed as it made his sickness worse. He was violently sick every day due to his treatment but he was sick a lot more on the preventative antibiotics. I think he was given pozoconazole instead but I'd need to double check.
77. I wasn't asked for consent about the preventative antibiotics, the Cipro or any others. I was just told that it was happening.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

78. On 13 August 2018, I woke up to find them removing cladding from the side of the RHC. There was a blue film on the windows to protect the glass and scaffolding was getting put up. I was never told this would be happening.
79. While the cladding was getting removed, we were told that we weren't allowed to use the entrance to the RHC and we had to go through the entrance to the adult hospital. The entrance we were asked to use was where everyone goes to smoke. There were people coming and going through that entrance. Staff were happy for children to be going through smoke and goodness knows what else but not through the other doors because of dust. I wasn't happy about this. Adults were standing coughing and spluttering everywhere. It was not very nice.
80. The windows in the room couldn't be opened. There was no option to open them even if you'd been allowed to open them.
81. From about June 2018, we kept getting moved rooms due to cleaning. They had what looked like external people come in to do the cleaning. Once the

children had vacated the rooms, there was a plastic sheeting went over the door that would be taped off and there would be a machine on the outside that went through the plastic sheeting and it blew a fog or mist into the room. I think it was for 24 hours that the room would be locked off for until you were allowed back in.

82. [REDACTED] has been left with mobility issues since his stay in RHC/QEUA. He walks on his tip toes and he's had to have several serial castings done on his legs which means they put his legs in plaster cast for weeks at a time to try and bring his feet down. He now has to wear splints on both feet for 6 hours a day whilst he's at school to try and encourage his feet to stay flat. This is partly because of the medications he received to treat his cancer as it can break down the muscle in the legs. I think it is also due to him being bed bound. [REDACTED] was in source isolation a lot because he picked up infections. If he hadn't have picked up the infections and been in source, he would have been more mobile and able to walk up and down the ward to get exercise. He was a tip toe walker before he went into hospital but it wasn't as bad as it was when he left the hospital. I think the issues with the hospital mainly impacted [REDACTED]'s mental health.

83. I did not like the fact that you couldn't open the windows. The rooms were sometimes really hot so the temperature spikes could have just been down to that. Then there would've been no need to put him on the protocol and give him antibiotics he maybe didn't need. Even the nurses would come in and comment on the heat. The staff used to turn the ward lights off to try and cool the ward down. It was worse when you were in isolation as you weren't allowed to open the door due to infection control.

CLEANLINESS

84. Another point I want to raise is the cleanliness of ward 2C. I'd asked for bedding for myself for the parent's bed and I was handed a blood stained blanket. It was disgusting. I can't remember if it was a nurse or an auxiliary

that gave me the blanket but I told them they couldn't give me that and I handed it back. I asked why it hadn't been checked beforehand but they weren't interested.

85. Nurses just kept coming in and out of the room as normal; just washing their hands, no aprons and no masks until [REDACTED] was diagnosed with flu. [REDACTED] had already been in the hospital for two or three days with nurses being in and out so them spreading the flu was a worry for me.
86. [REDACTED] was violently sick multiple times every day and sometimes had diarrhoea where unfortunately, he didn't always make it to the toilet in time. We used to be able to change the bed ourselves but when everything started happening on the wards, when all the room moves were happening and the rooms were being cleaned with cleaning mist, we could strip the bed but had to ask the nurses to bring bedding for us. Sometimes they couldn't bring it straight away so we'd be there for an hour or two waiting for bedding and had nothing clean to lie on, just the mattress which wasn't comfortable for him. When you're sitting in the room, you can see the trolley with the clean bedding just two seconds down the corridor and you think "Why can't I just grab a clean sheet and put it on the bed for him".
87. The dirty bedding could be left sitting for a long time. It was the same with his stool and urine samples on ward 2A. Nurses wanted to check how much urine he was out-putting each day so they could measure his fluid intake and output. When [REDACTED] had the VRE he had to submit stool samples all the time. We weren't allowed to take the samples to the sluice which was on ward 2A. The sluice was a room with two sinks in, a couple of bins and the disposal for the samples. At first, we were allowed to take it down ourselves. We would just put the name on it and the nurses would deal with it but when that all stopped, we would be asking the nurses to come in and take the samples from the room. I think this practice changed towards the end of May 2018.

88. Sometimes the samples were left for hours and hours and you could have 6 or 7 sample pots sitting in the bathroom waiting to be collected. As you can imagine, sitting in a room that's warm, the smell was bad. I didn't think it was hygienic them being left to sit that long but again, it was down to the nurses' workload. They just had so many extra things they had to do that parents had been allowed to do before and now weren't allowed to do. It had all been put on to the nurses. Nurses had a lot more tasks to take on due to new protocols for infections on the ward.
89. When the nurses came in to do the observations, they would forget to take the sample pots away with them. It got to the point where I had to say to them if they're not going to collect samples, I'm not going to keep putting them out and I'm going to let [REDACTED] go to the toilet normally as it's not hygienic for them to be left sitting in the room.
90. There was a smell of sewage at the hospital when you were going outside to inside from the carpark into the hospital. It was disgusting. Not what you want to be smelling when you're going into a hospital. You could smell it on every ward.
91. We were aware of smells on the ward too. On one occasion, in ward 2A, it smelt like gas. It's hard to describe the exact smell, it was like a burning gas. One of the nurses came in and said she didn't know what it was. She got other nurses and the nurse in charge to come in to see if they could smell it too. The nurses were debating whether to pull the fire alarm or not but they decided it was in fact fine.
92. [REDACTED] had a fantastic relationship with one of the weekend cleaners. The rooms were cleaned daily but I would never put [REDACTED] on the floor. If you wiped the floor with a wipe after it had been cleaned, you would see that it was still dirty. It appeared the cleaners used the same water and same mop for every room but I really don't know if the water was changed or not. I never saw them change the water in between rooms.

93. There was a cloth over the mop which I'm not sure about. It looked like it went into a bucket of water, different to the stuff they dipped the mop into clean it but it was the same one for each room.
94. The cleaning was different when you were in isolation as the rooms were cleaned twice a day. I think it was once in the morning and once in the evening. Staff used to wear aprons when they came in to clean during isolation.
95. I saw on the news about the pigeon droppings at the hospital. I wasn't told by a staff member it was an issue. I asked the Nurse Practitioner a question about the news and asked if it would put [REDACTED] at extra risk being here. She said, no it's fine. She went away but then came back saying [REDACTED] was well enough to go home. It gave the impression that anyone who didn't need to be in the hospital was well enough to be managed at home. It looked as though you were better being managed at home rather than being in that environment.

OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HIS FAMILY

Overall emotional impact on

96. [REDACTED] was affected mentally more than anything. The periods of source isolation when he wasn't allowed visitors were difficult. As a child, you want to be with other children. You want that sort of stimulation from doing normal activities and that was all taken away from him with the diagnosis, isolation and not having people there.
97. With [REDACTED] not being allowed visitors, it was just me and my mum that were there all the time. He now has really bad separation anxiety. Although he loves spending time with my mum, dad and family, if I say to him he's going

to be doing something at the weekend and he finds out I'm not going to be there, he won't go.

98. Even going to school sometimes, he's terrified about leaving me. It's not been helped by covid and being off school. We had gotten back into a routine then the lockdown happened and it's like being back in the hospital situation and he's got really bad separation anxiety from that.
99. [REDACTED] was under the care of CAMHS. He was on the waiting list for a year before he was seen. Even then, it was me they had video calls with. The psychologist at CAMHS said [REDACTED] needs tested for ADHD at school as he's displaying a couple of symptoms and they need investigated. Whether this was always going to be the case or whether it's been triggered by his time in hospital, we'll never know.
100. [REDACTED] can be very up and down. His behaviour can be very erratic at times. He can go from 0 – 100 in the space of a second. He can be sitting quietly and I'll ask him to do something and he can have an aggressive outburst. He's not aggressive but he has lashed out at me a couple of times. Whether this was triggered by the hospital and the situation, again, we'll never know.

Overall emotional impact on witness

101. You're already in a stressful situation when your child has cancer without having to worry about all the other things going on in the hospital or about your child getting an infection. I tried to stay cool, calm and collected in front of [REDACTED] and didn't discuss anything in front of him; he's got the personality type where he will stress and worry about things. I was stressing and panicking.

Overall emotional impact on family members

102. My mum was very angry and upset when the issues started to appear in the media. She had to watch her grandson getting treated at the hospital with all of the other issues going on.
103. My mum used the parents' kitchen in 2A quite a lot. She would get our daily food and drinks in the morning and prepare lunches with our names on before she came over to us. She would store these in the fridge for us and make us coffee. When the parents kitchen closed in ward 2A, that was taken away from her and she felt useless as she couldn't do anything else to help.

COMMUNICATION: GENERAL

104. When [REDACTED] was first admitted, his consultant, Dr Chaudhury, gave me a print out of the protocol [REDACTED] would be on. This had all the names of the different chemotherapies he would be on and the potential side effects which she explained he could get from them.
105. I felt I was well informed about his treatment. There was one time I asked the nurse if she could tell me the names of the medications and she wrote them down, which each one was for and why he was getting it so I had a physical copy of it.
106. I was told by a mixture of nurses and consultants about the possible side effects and things that can happen during treatment. They said that it won't be the treatment that causes him to be really ill, it could be an infection. I can't remember exactly who said this.
107. The communication about [REDACTED]'s treatment was like night and day compared to communication about other things. Why he was getting put on precautionary antibiotics wasn't explained. The room moves weren't clearly explained. The reasons why chemicals were being poured down the drains, why the ward was having to close and the situation with the pigeon droppings weren't explained either. These were just brushed over as if staff

didn't want to answer them. We were just told, it's precautionary, we have to do it. There have been infections and we have to get on top of it. Staff never went into details about anything. It was just brushed over.

108. We were not always given notice of room moves. They would come in and tell you that you're moving but not why.
109. On 18 May 2018, [REDACTED]'s friend came to visit him, which they'd previously been allowed to do. We were told that day that it was only siblings that were allowed in. It was the day his friend came that staff told him they're not allowed in. We were never told this was stopping.
110. [REDACTED] had a temperature spike of over 40 degrees on 21 July 2018. He was left for hours without any calpol. Nobody told me at the time that they'd actually suspected sepsis, which made his wait for the calpol worse. I found out about the suspected sepsis from his medical notes. They should've told me or my mum if that's what they suspected.
111. On 4 September 2018, we were supposed to be getting discharged to back to the CLIC Sargent and were unaware [REDACTED] was going to be discharged home that day. I was completely unaware that [REDACTED] was being discharged that day. No one had mentioned it at all, even on the doctors' rounds that morning nothing was said, as far as I was aware he was to continue being an inpatient for the remainder of his treatment. All of a sudden, we were told they needed the room and [REDACTED] was well enough to go over to CLIC Sargent House. I decided to take him home as we hadn't been home for a long time. I took him home that night and took the opportunity to take some of our stuff home as we'd gathered quite a lot of things.

COMPLAINTS

112. My mum complained to the nurse in charge when [REDACTED] had been given an overdose of medication on 6 July 2018. The nurse in charge told my mum

that she would fill out a form that this had happened. We were never shown the form or asked to sign it. She informed my mum that on a monthly basis staff go through these forms and see what issues had occurred that month then they address it with the nurse.

113. We heard nothing back from this and personally, I think it should've been dealt with there and then, especially with an overdose.

114. There was an occasion when the First Minister and Health Secretary were at the hospital for a visit. I think it was maybe for Nurses Day. We'd been in a roasting hot room and my mum decided to speak to the First Minister or Health Secretary about the heat in the room. I think it was the Health Secretary that she spoke to and she said they'd get a member of the Management Team to investigate and have a look at it for us. A guy turned up wearing a suit and he had ladders with him. He put a probe up into the vents system and said everything was fine. That was the last we heard.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

115. I have heard about the Oversight Board but I wasn't directly involved with it. I used to see the updates that were posted but had no direct involvement with them.

116. [REDACTED] was not included in the Case Note Review. I got a letter telling me he wasn't but I can't remember the exact wording. Maybe because his case wasn't "important enough", I don't know.

117. I'm not a member of any representative groups.

CONCLUDING COMMENTS

118. At the time, you're just trying to get from one day to the next and it wasn't until [REDACTED] was out of treatment that I've sat back and thought, "That was

actually horrific having to deal with that on top of everything else". You're already in a horrid situation and then having to deal with everything else on top.

119. There should have been more communication from the staff to the parents. That hospital was our home for 6 months. We were there day in and day out. There should have been more communication about what was going on. Yes, it wouldn't have been nice to hear and it would have been stressful but at least we would've been prepared and had knowledge instead of hearing it second hand from newsreaders, newspapers or news articles online.
120. If we knew exactly what was going on or what they suspected by cleaning the rooms, or cleaning the pipes, or pouring chemicals down drains, it would have made things easier to understand and deal with rather than just being left in the dark.
121. It was quite stressful hearing all the different things that have come out. In some sense you think, thank god it's not me in that situation but in the other sense, you think it quite easily could have been me. We were there at that time. We were in the hospital when everything was happening. It's not nice to see certain things in the press and things that have come out since.
122. To be told it's not the treatment that makes them ill, it's infections, then to find out children are getting infections, makes you more stressed. It shouldn't have been happening. [REDACTED] was there to get better, not worse.
123. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

APPENDIX 1 – LY/01 – TIMELINE

- 7th April 2018 – ██████ showed signs of being unwell complaining of a sore head, that things were upside down. He also started complaining about a sore tooth.
- 9th April 2018 – Appointment at the local dentist. He had an abscess which needed to be removed.
- 10th April 2018 – ██████ still had a temperature so Leann took him to the GP. Local GP was closed that day so he was taken to a GP in the next village. There he was told that he had an ear infection and was prescribed medication.
- 12th April 2018 – ██████ was screaming in pain. He received an emergency GP appointment. He did a urine sample that day at home. Leann took this sample back to the GP and was told by the receptionist that the doctor had looked at it and everything was fine which Leann disputed. She phoned NHS 24 that evening and took ██████ to an out of hours clinic in Paisley. They asked for him to be taken to QEUH children's hospital for further investigations. Leann and attended QEUH in the evening and remained there.
- 13th April 2018 – In the early hours, blood tests were done and Leann was told that ██████ had raised LDH levels in his blood and more tests were carried out.
- 14th April 2018 – ██████ was moved from CDU to ward 2C. Room number unknown. Haematologist said a bone marrow biopsy would be carried out.
- 16th April 2018 – Bone marrow biopsy carried out
- 17th April 2018 – Urgent blood tests conducted and Leann was told that abnormal cells had been identified. Leann was told that ██████ had cancer but he was not formally diagnosed on this date. That day moved from ward 2C to ward 2A, room 16.
- 18th April 2018 – ██████ given formal diagnosis of stage 4 burkitt lymphoma leukaemia. He went for an MRI that day and they were then told he had cancer around his brain and CNS.
- 20th April 2018 – ██████ had a central line fitted.
- 21st April 2018 – ██████ started chemotherapy. 1st round.

WITNESS STATEMENT OF LEANNE YOUNG

A33675140

- 15th May 2018 – █████ put into Source because he had diarrhoea and was being sick. Moved from room 16 to room 9. He moved rooms because a new person came on the ward.
- Around this time █████ had VRE vancomycin-resistant enterococcus an environmental bug. Difficult to know how long he was ill with it as he had it so much. On this occasion or possibly at another point when █████ had VRE, stool samples were taken to see if he had any other bugs. Leann kept asking for the results and was not told anything. She came to find out later that there were two weeks' worth of stool sample results that had gone missing.
- 18th May 2018 – █████'s friends from school came to see him and were denied entry to the ward on the basis that no children were allowed in, only siblings. This was extremely upsetting for █████ who is an only child and no one had communicated this to them.
- Around the 18th May 2018 or the surrounding days – Leann was told by the nurse that they had to pour a chemical down the shower and toilet of the room that █████ was in.
- 1st June 2018 – █████'s infection markers were raised: he had a fungal infection. Leann was not told the name. Further tests were done to check if it had spread. These investigations included an eye examination, an ultrasound and CT scan. She was told that he had a ball of fungus on his liver. He was put on medication to treat this (a higher dose) and his chemotherapy was delayed by 10 days. Leann was given no further information but upon reviewing █████'s records later on it states that he had *Aspergillus fumigatus*.
- 5th June 2018 – Moved from room 9 to a room that had a double door entry (Leann cannot recall the room number). They were told about this move last minute and were told he was moving because the room needed to be cleaned. On that day they were also advised by a doctor that all children who had central lines were going to receive a medication as a precautionary measure called Ciprofloxacin. Leann was not told why.
- 6th June 2018 – █████ was moved rooms from the room with the double doors. The family were told they were moving in the morning but did not move until 10pm that night. The family were not allowed to take any of their things with them. Stuffed toys, games, books, everything except the clothes on their back

had to stay for cleaning. The room was then sealed with a plastic covering and a mist was blown into the room which Leann was told was a cleaning agent. Leann thinks they were moved to either room 14 or 15. The room was very small is all she can remember about it.

- Around about the time they were in this room, Leann recalls being told that the hospital were going to change the pipes behind the sinks in the room because there were children getting water infections from bugs that were sticking to the plastic in the pipes. Leann can't remember if they had to leave the room for a little while, when this work took place or if they were moved rooms.
- 7th June 2018 – ██████ was put back in source with VRE. Leann can't recall how long he was in isolation for.
- 10th June 2018 – Blisters appeared on ██████'s body on one side. He started receiving acyclovir by IV because the doctors thought he had chicken pox even though he had already had it the year before. A swab was taken and Leann was told that if the swab was positive he would be moved off the ward because of the risks it would pose to other patients/pregnant nurses.
- 12th June 2018 – Swab is negative for chicken pox and the medication is stopped.
- 14th June 2018 – A consultant advises that a mistake has been made and that the fungal infection was all clear and that ██████ did have chicken pox.
- 17th June 2018 – ██████ started his 3rd round of chemotherapy.
- 6th July 2018 – ██████'s blood counts had not recovered enough for him to complete the last part of cycle 3 of his chemotherapy. He was therefore given permission to attend a wedding that day. As part of this, too much anti sickness medication was signed off by the nurses due to a change in shift. The consequences of this were that ██████ was not allowed the medication for a long time which made him very violently ill.
- 7th July 2018 – Leann's mother, ██████ put in a verbal complaint to the nurses about it. A form was completed and the family heard no more about it.
- 11th July 2018 – ██████ started the 2nd part of the 3rd cycle of chemotherapy. He had 5 teeth removed on this date which was a consequence of the

chemotherapy. The teeth had holes and this left him at higher risk of infection until they were removed.

- 11th July 2018 – 21st July 2018 – Leann thinks [REDACTED] may have moved rooms in this time period but she can't recall for certain. What she can recall is that from the day when he had his teeth removed to the events of the 21st July, she was in different sections of ward 2A.
- 21st July 2018 – [REDACTED]'s temp spikes to over 40 degrees, he was left for several hours before he was given calpol to help reduce his temp. The nurses were busy with other matters/too busy to get to [REDACTED]. Generally, there were many delays because the nurses were extremely busy.
- 13th August 2018 – 7:53am workmen appeared outside [REDACTED]'s bedroom window removing the cladding. This took place for weeks and weeks and there was a lot of scaffolding around the children's section.
- 16th August 2018 – [REDACTED] started his 5th round of chemotherapy/ his 1st maintenance round.
- 26th August 2018 – Put into source with VRE.
- 31st August 2018 – [REDACTED] was told that his last bone marrow biopsy was all clear and his cancer was in remission. He still had another round of maintenance therapy to go through in September.
- 4th September 2018 – Allowed home for a few days.
- 9th September 2018 – admitted back because he was sick at home and his NG tube came out. He returned to ward 2A. Room unknown.
- 12th September 2018- Final round of chemotherapy into ward 2A. Room unknown.
- 17th September 2018 – [REDACTED] received his last dose of chemotherapy and he was discharged over to the CLIC Sargent House. He was not allowed home because his blood counts would crash after chemo so he needed to be near the hospital.
- 18th September 2018 – Leann finds out on the news that 2A and 2B are closing and the wards are moving to the adults hospital. They had been in the day before and there was no indication that this was happening, nothing was mentioned. Leann was due to take [REDACTED] back that day so she phoned the

ward to find out what she should do and where she should take him. The staff knew nothing about the move. Leann was told to take ██████ to Day care.

- 20th September 2018 – Leann took ██████ to 2B to get his bloods checked. She was given a letter saying that the ward was closing and they were going to 6A in the adult hospital. They were not told why.
- 25th September 2018 – they were still staying at CLIC Sergeant House. He spiked a temperature and had to be admitted. He was therefore an inpatient during the move on the following day.
- 26th September 2018 – Leann described the move as being like “organised chaos”. The nurses were trying to look after everyone and move everything. ██████ was asked to wear a mask over his face. Mid-afternoon ██████ was moved over to 6A. Room number unknown.
- 12th October 2018 – ██████ was allowed to go home to the CLIC House
- 19th October 2018 – Went to Ward 6A to have his central line cleaned and bloods checked. He had to walk through the whole of ward 6A to get to day care.
- 14th November 2018 – The central line was removed
- 10th December 2018 – ██████ had Respiratory syncytial virus RSV. He was in a different ward, possibly 3. It was not 6A. He was admitted for 3 or 4 days.
- 6th January 2019 – ██████ is diagnosed with shingles and admitted. He was not allowed to ward 6A so he was put into ward 2C.
- 18th January 2019 – Leann saw on the news about the pigeon droppings story. ██████ was in hospital when Leann read this. She asked if ██████ was at a higher risk because of this and the nurse’s response was that he could go home that day. She did not answer the question, just that he could go home. He was discharged.
- 10th February 2019 – ██████ spiked a temperature. There was no space on ward 6A to admit him so he was put in ward 2C. Tests were conducted and on the 12th February he was diagnosed with flu. He was discharged 3-4 days after this admission.

Aftercare

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For 6 months after this he continued taking the prophylactic antibiotics and attended for check-ups. These were every 2-3 weeks to make sure he was ok, then this changed to once a month then after a year this changed to every 3 months. Now he sees the hospital every 6 months. First 6 months he attended day care for appointments, after this it was the clinic in the main atrium at the hospital.