

## Scottish Hospitals Inquiry

Witness Statement of

**Sharon McAllister**

### WITNESS DETAILS

1. My name is Sharon McAllister. I was born on [REDACTED]. I am [REDACTED] years old. I am a full time mother.
2. I am the mother of [REDACTED]. [REDACTED] date of birth is [REDACTED]. She is [REDACTED] years old.
3. I live with my [REDACTED] children, [REDACTED] in Rutherglen, Glasgow.

### OVERVIEW

4. My daughter is [REDACTED]. [REDACTED] was diagnosed with Acute Lymphoblastic Leukaemia (ALL) in February 2019 when she was 8 years old. [REDACTED] was treated in the Queen Elizabeth University Hospital (QEUH) between February 2019 and July 2021. Her chemotherapy finished on, 3 May 2021 however, she was still attending the hospital for treatment. She attended the hospital as an in-patient and as an out-patient for over two years. [REDACTED] still attends as an out-patient for blood tests and bone marrow aspirates.
5. [REDACTED] spent time in ward 3C of the RHC and ward 6A of the QEUH. Ward 6A was known as the children's cancer unit. I stayed with [REDACTED] during most of her admissions to hospital as an in-patient and an out-patient. I can speak to the experience that [REDACTED] and I had in these wards.
6. There are some specific events that I would like to mention. [REDACTED] had a number of infections during her stay at the hospital. Within the first few weeks

of her admission in February 2019, [REDACTED] contracted a staph infection that had possibly developed into sepsis. In her medical records this is referred to as staphylococcus aureus. Through reviewing her medical records I have also uncovered through my solicitors that on 22 March 2019 [REDACTED] developed Enterobacter cloacae. I have never been made aware of this before now. There were issues with the water supply during the latter part of [REDACTED] admission to hospital. I believe that [REDACTED] was prescribed preventative antibiotics in 2019 which may be connected to the issues with the water supply. I will come on to talk about these events in more detail.

### **FAMILY BACKGROUND**

7. I live with my [REDACTED] children in Rutherglen. [REDACTED]  
[REDACTED].
8. [REDACTED] turned [REDACTED] in [REDACTED] this year. She was 8 years old when she was first diagnosed. [REDACTED] is a very quiet girl. She's always been quiet and happy. She was just a nice wee girl. [REDACTED] was into dancing when she was younger but she was very quiet and didn't like being away from me. She did kickboxing classes with me but when the pain started, she just couldn't cope with continuing the kick boxing. Before her treatment, [REDACTED] also loved swimming but she had to give that up as she had a central line fitted.
9. As a family we liked the outdoors and indoors. We liked quite a mix of activities. We liked going for walks through the woods and parks. We always went to parks. We liked wee hotel trips to go to the swimming. We loved going on holiday. We went on holiday twice a year.
10. Prior to [REDACTED] diagnosis, she was a happy, well child. [REDACTED] had temperatures when she was younger but apart from that, she was well and never up or down with the temperatures.

### **SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT QEUH**

## **Admission to hospital: February 2019**

11. [REDACTED] was diagnosed with ALL in February 2019, when she was 8 years old. She had been complaining of back pain at the start of December 2018. We were back and forward to the GP where we were told there was nothing wrong. We started attending the A & E department at the QEUH where they carried out X-rays. Initially we were told the X-rays were fine but then I got a phone call the next day to say [REDACTED] had fractures on her spine and they were concerned it was osteoporosis. I don't think the doctor knew for certain what it was as he was asking me all sorts of questions about [REDACTED] colour. I said she needed a scan done. He agreed that a scan was appropriate. He put the referral through as urgent.
  
12. [REDACTED] was at a point where she couldn't get up without help as she was in so much pain. The local GP came out and put her on oramorph which is liquid morphine. [REDACTED] dad and I were having to lift her out of her bed. She was screaming with pain so I called the hospital and asked to speak to the doctor who was dealing with [REDACTED] MRI scan. The doctor called me back and I said that it wasn't right [REDACTED] being left on morphine and being in this much pain at 8 years old. He agreed and told me to bring her up and she would be admitted to the ward.
  
13. [REDACTED] was admitted to ward 3C in the RHC. This would have been 9 February 2019. On 12 February 2019, [REDACTED] had a bone marrow aspirate carried out and on 13 February 2019, Dr Shazia confirmed it was ALL. [REDACTED] was then transferred to what we were told was the cancer unit in the adult hospital on 14 February 2019. At this point we weren't told anything about what to expect.

## **[REDACTED] initial treatment: February 2019 – 19 April 2019**

14. [REDACTED] originally was supposed to get a port put in but it didn't work. On the 16 February 2019, [REDACTED] was fitted with a central line. She was given

chemotherapy at the same time. [REDACTED] was meant to receive chemotherapy for four weeks but we ended up being in the hospital for nearly three months.

### **Experience on ward 3C: 9 February 2019 – 13 February 2019**

15. When we first went into ward 3C, we were in a shared ward for a day or so before being put into a separate room. There was a pull-out bed in the room for me to use.
16. There was a small playroom at the top of the ward but there wasn't much else on the ward for children.
17. There was a kitchen that I could use to make tea, coffee or toast. There was always something in there.
18. [REDACTED] had a cannula fitted but because it had been in too long and not used for anything, it was in the wrong place so [REDACTED] developed an infection. She was put on antibiotics for this but I wasn't told at the time about this. I had to ask what she was being given. I think it was the nurses I spoke to about this. We were never given any information about any infections that [REDACTED] developed. We were never told what it was, where it had come from or anything that would have fully informed us of what was going on.
19. We were then told that [REDACTED] would be admitted to the cancer ward in the adults hospital but that was all we were told. Nobody came and spoke to us about what to expect or what treatment would be.

### **Experience on ward 6A: 14 February – 19 April 2019**

20. The cancer ward in the adults hospital was ward 6A which was a good bit away from the RHC. There were no electric doors either so the doors had to be held open. We had to share lifts with other people too. When we arrived on the ward, we came in the back way. It was a long journey between the two wards.

We didn't know what to expect and nobody had told us what to expect so when we walked in, we saw all these children through the windows with no hair. We thought, "God, what do we tell our daughter?" It was at this point that it hit us that our daughter had cancer. We were trying to hold it together and not break down but [REDACTED] was asking what was wrong.

21. I can't remember if [REDACTED] was transferred to the cancer ward in a wheelchair or on a bed but she was lower down and couldn't see the children through the windows. We knew we couldn't hide this from her though.

22. We didn't even know who [REDACTED] consultant would be at this point. We just assumed it would be Dr Shazi as she was the one who had told us about the diagnosis.

23. We were put into a single room which was bigger than the room in ward 3C. There was a wee fold up bed in the room for me to use. The room also had a big machine in it. We were told that it was a machine that was designed to clean the air.

24. There was no parent's room in ward 6A and nowhere for children to play. We were put in a room and left there. We kept asking for someone to come and speak to us and tell us what was happening. That was really hard. I explained that we didn't know what [REDACTED] treatment was going to involve or for how long it would take. A nurse agreed with me that someone needed to come and speak to us. She said someone should have spoken to us and that's why Professor Gibson ended up coming to speak to us the next day. She took us to another room. I'm not sure if Dr Shazi was on holiday or away but Professor Gibson became [REDACTED] consultant.

25. [REDACTED] had her central line fitted on 16 February 2019. It was meant to be fitted before this but something happened so she didn't get it done when she was meant to. She was meant to be getting a port but it didn't work. I asked what the central line was for and a nurse took us round to speak to a wee boy.

The nurse asked the wee boy about his line and asked if he would mind showing us. The nurse showed us the line and a port. This was just before [REDACTED] had her own central line fitted.

26. [REDACTED] central line wasn't working properly from day one. It was taking medicines in but it wasn't giving out blood. Sometimes it worked and sometimes it didn't so they started using thumb pricks on [REDACTED] to take blood. They kept persisting with the line though, even though they knew it wasn't working.
27. [REDACTED] treatment lasted a lot longer than the four weeks it was initially supposed to. She had infections which sometimes resulted in her chemotherapy being stopped but she was also having a reaction to some of the medications. [REDACTED] ended up having a chemotherapy injection, a PEG jag it's called but that gave her blood clots that staff didn't pick up on. I said to the consultant Annamarie that [REDACTED] wasn't right as she'd been getting headaches and asking for the light to be turned off. I asked for a scan to be done as I knew something was wrong. I was told they would wait a couple of days and see what happened. I said, "Can somebody please arrange a scan as something's not right with my daughter. I can tell. Please listen to me." They did do a scan and found [REDACTED] had a massive blood clot on her brain. I think this was mid-February when this happened.
28. [REDACTED] got two injections a day to treat the clots. They were initially going to give her medication to dissolve the clots but it was too dangerous as the one on her brain was so big. There was also a clot at the bottom of [REDACTED] central line which is probably why it hadn't been working. She still had her chemotherapy but sometimes there were delays in her treatment for a variety of reasons, for example if they suspected an infection.
29. When [REDACTED] received the injections, her heart rate became really high and she just wasn't right. I kept saying to them that her heart rate was going too high and the machine's alarm kept going off. Nurses kept coming in and just pressing the button to stop the alarm going off though. It went on for days. I

asked the nurses to stop putting the alarm off and get someone in to find out what was wrong. Professor Gibson came in and she was furious because the nurses shouldn't have been turning off the alarms. She immediately organised for [REDACTED] to have scans. It turned out [REDACTED] had blood clots in her lungs and at the bottom of her line too. They weren't able to give her treatment to dissolve this clot though as the one in her brain was so big, it was simply too dangerous. They also believed that there was a possibility that there was a clot at the bottom of her line.

30. During [REDACTED] time on ward 6A, there was also a point where she was given too much morphine. She was in an induced coma and Professor Gibson stepped in and told them to stop the morphine. I can't remember when this was.

31. [REDACTED] was in source quite a lot. I think they used to put the children in source as they didn't like them going out and about. The children would get diarrhoea with the IV antibiotics but as soon as that happened they would get put into source, even though it was the antibiotics causing it.

32. [REDACTED] then developed an infection in her leg. She had been very unwell but I just kept getting told they didn't know what was wrong with her or they didn't know what was going on. They knew there was something wrong but they couldn't figure out what.

33. When [REDACTED] was going to theatre to have the infection looked at in closer detail, because the doors weren't automatic, she getting battered into doors. There was nobody to help her to go down, just two nurses and they laughed at [REDACTED] being battered into the doors. I didn't think it was funny; my daughter was sick lying in that bed and I said so to the nurses.

34. On the way back up from theatre, they made a big mistake. [REDACTED] was attached to a drip stand on her central line and they tried to move her from the bed she was on in theatre to her own bed with the line still attached. If I hadn't

been there and screamed at the nurse to stop, [REDACTED] central line would have been ripped out of her body. The nurse said it was a good job I had been there! This happened in the RHC.

35. I asked what would happen if [REDACTED] took really unwell between the RHC and the QEUH. The nurses said, "Oh, just thank God that hasn't happened." We would have to get [REDACTED] out of her room, through corridors, wait for lifts, go down in lifts, walk through some more corridors then walk to theatre. It was at least a 5 minute walk but it was just brushed off when I raised it. They just said they would deal with anything that happened but where?!

36. When [REDACTED] was in theatre regarding her infection, she had her feeding tube fitted at the same time on 18 March. Her mouth was full of sores but that's quite common with children and chemo so we had no choice but to also have a feeding tube fitted.

37. [REDACTED] had her central line removed on 31 March 2019 because of the clots she had at the end of her line. Professor Gibson wanted to keep the line out as long as possible although they were talking about getting another one put in because [REDACTED] would need it for the harder stages of her treatment. She kept getting cannulated in the meantime though which was very stressful. All of [REDACTED] veins had collapsed so they were struggling to get a vein. There were people coming up from other areas with big machines to do scans of her veins because the vein finder wasn't working either. They had to scan her for a vein though as she needed her chemo. That was hard and there was also a risk of infection because they had to keep going in and out with cannulas all the time.

38. [REDACTED] eventually got a PICC line in her arm but until 19 April 2019, her treatment was given through cannulas.

**Completion of [REDACTED] treatment: From April 2019**

39. [REDACTED] was discharged on 19 April 2019 but she was in for theatre on 23 April 2019 for a lumbar puncture and chemo.



40. On 25 April 2019, [REDACTED] was back at the hospital to get her leg checked as it was really bad at this point because of the infection.
41. [REDACTED] then attended Day Care in ward 6A on 30 April 2019 for chemo. [REDACTED] treatment continued like this until July 2019. She would be in for chemo at Day Care and some appointments were at the theatre so she could have a lumbar puncture done.
42. On 4 July 2019, [REDACTED] was back in Day Care for one of the big chemos but there were no beds available. She was really unwell that day and feeling very sick. She got her chemo through a drip whilst she was sitting in a wheelchair. I was really annoyed at this as because [REDACTED] was unwell, she ended up spiking a temperature when we were at the hospital and we had to stay in. They took bloods but I was never told what had been wrong with [REDACTED]. She was discharged on 8 July 2019.
43. [REDACTED] had a few more admissions where she had spiked a temperature. They usually keep you in if that happens. They would test [REDACTED] for infections and give her antibiotics but I was never told if she had an infection or not.

#### **WATER: EVENTS INVOLVING WATER SYSTEMS**

44. I started hearing things through the parents group about there being something wrong with the water. When we were first in the hospital, I didn't notice anything but some of the nurses were quite vocal telling us not to let the children near the water. Signs then started to get put up stating not to use the water and we were given bottles of water to drink. I think this was between September and October 2019 but I can't remember exactly.

45. We were told to run the shower for three minutes before using it at one point too but I didn't want to put my child in it and I can't remember exactly when this was.
46. We were very concerned about what was going on and no one was explaining it to us. We were also told at this point to use bottled water. We were told from the start of us going to ward 6A, that we were not to drink the water. It was the nurses telling us that.
47. When we were first admitted to the hospital, the nurses would bring in jugs of water to the room. We were told not to drink the water in the room from the outset. We were never told why. We were originally told that we were allowed to brush our teeth with the water but then that changed to us being told not to brush our teeth with the water. This coincided with us being put on the ciprofloxacin. The nurses eventually told us that it was ok to use the water again. I can't remember when this was though.
48. We also saw filters on the showers right from the point we were admitted to the hospital.

### **HEALTHCARE ASSOCIATED INFECTIONS**

49. [REDACTED] had a few infections when she was in the hospital, including one where I thought we were going to lose her.
50. [REDACTED] would spike a temperature and they would start her on antibiotics but I was never usually told what the infection was or what antibiotics [REDACTED] was given. They would keep telling me [REDACTED] was a medical mystery as sometimes they didn't know what was wrong with her. They would never explain what was going on. It left us extremely scared.
51. On 15 March 2019, [REDACTED] was in the QEUH and had been unresponsive for a few days. There were other teams coming up to see her including the team from neurology. Professor Gibson was great but she was very scared and

when we asked what was wrong with [REDACTED], Professor Gibson said she didn't know. This was why she was so scared. She said they knew there was an infection but they didn't know where it was and [REDACTED] still hadn't been responding to anything. Professor Gibson arranged for the team from PICU to come up and see [REDACTED]. At this point, only my husband was allowed to stay as they told us it had to be just one adult. [REDACTED] was also receiving one to one care.

52. [REDACTED] was getting blood tests done all the time but we were never actually told what that infection had been. Every time I asked someone, I was just told "We're looking into it. We've contacted different hospitals".

53. [REDACTED] eventually came round but she was still very unwell. Her electrolytes had gone crazy and were at a very dangerous level. They thought it might've been due to a bone infusion, due to the fractures on her spine, but they just didn't know for sure. There was no treatment that we were made aware of, all I can recall is that there were constant teams of people going in and out of her room talking to each other but never to us. I would ask questions constantly to the point at one point I was told I asked too many questions by another consultant.

54. I recall that when she came around, [REDACTED] and I got her off the bed, as [REDACTED] couldn't really walk at the time, and we put her into a chair. I stripped her down and there were two sores on her leg. I asked the nurse to come and look at them. She apologised that she hadn't noticed them but we only noticed them as we had stripped her down. They should have listened to me sooner though when I said [REDACTED] wasn't right.

55. [REDACTED] was started on antibiotics for this but she had gone unresponsive. This was around 18 March 2019. Staff wouldn't cover her leg either. At this point we knew there was stuff going on at the hospital and we didn't want any sort of infection getting into [REDACTED] leg. I asked for her leg to be cleaned but Dr Cozens said not to touch her leg, just to leave it.

56. On 19 March 2019, [REDACTED] leg started weeping and the redness was spreading. After 48 hours, she should have had her antibiotics changed if they weren't working but this wasn't done. I said to the weekend doctor that they needed to change the antibiotics as [REDACTED] had been on them for more than 48 hours and she was getting worse, the infection was spreading. Her leg was a mess, it looked like a spider bite. The nurse kept saying it was looking a lot worse too. Nothing was done and nothing was marked to show the progress of the infection. There was a hole in [REDACTED] leg. It was full of pus and looked disgusting. They wouldn't clean it or dress it though. I eventually lost my temper with the hospital and this led to her antibiotics being changed and a request for the plastic surgeon team to look at [REDACTED] leg. The plastic surgeons had wanted [REDACTED] leg marked but when they came back after a few hours, this still hadn't been done. I had pictures of it though so was able to show them pictures from the day it had started and the progression. Later on, another plastic surgeon came up. He was meant to be finished his shift but he stayed on to do [REDACTED] surgery. Dr Cozens had wanted to wait until the Monday until he looked at it but the plastic surgeons said if we'd waited until the Monday, [REDACTED] might not be here. They said we had a very sick wee girl and that the wound was quite deep. They had cleaned out as much as they could and they said [REDACTED] may need a skin graft. She was going back to get it packed and cleaned before they could stitch it up. There were risks around this as well as she may have developed another infection if she had gone down the skin graft route.

57. We kept asking what the infection was and the surgeon said, "Let's just say it's one of those infections you read about in the papers". He was furious with the way [REDACTED] had been left. The lady surgeon that was with him came up to the ward wanting to speak to people. They weren't happy with the way [REDACTED] had been left. I think they also came back to the ward during the week to speak to members of staff because at the point they had originally raised this it was just weekend staff on and no one could answer them.

58. We were eventually told it was a staph infection that [REDACTED] had and that it can happen to anyone but I didn't agree with that as it had been going up her

side too. It left me believing they were covering something up, but they said no it was a staph infection. Originally we were told it was one of the bugs you read about in the papers by the plastic surgeon when he was angry about how [REDACTED] had been treated. They thought it was that but it wasn't. They did tests to look into this but I was not made aware of the results

59. As part of this process my solicitor has identified a test result in [REDACTED] records that shows that she tested positive for *Enterobacter cloacae* on 24 March 2019. I have never been made aware of this result. I have provided this record to the Inquiry for their consideration. I am angry to find this out. No one ever advised me of this, and it was right in the period when [REDACTED] was seriously unwell. Is this the reason the sores developed on her leg? We have been advised that we were not eligible for the Case Note Review but this record would suggest otherwise.

60. [REDACTED] had her central line removed on 31 March 2019, due to the clots she had at the end of her central line. [REDACTED] had the bigger clot in her brain for a long time. They said it was one of the biggest they had ever seen. They were worried more clots would appear if they kept her central line in so it was removed. However, when they removed it, they realised [REDACTED] had a line infection. She never had another line fitted after this, she would receive cannulas instead.

61. She had a rash all round the line and it looked crusty. I asked about it and I was told she had a wee infection. I was never told what the infection was or how it happened.

62. From 31 March until she was discharged in April 2019, I am not aware of her having developed any other infections, however she was always unwell, no one was communicating with me about what was going on for her and there were a lot of things going on so it is entirely possible there was another infection.

## **PREVENTATIVE MEDICATION**

63. ██████ was prescribed posaconazole when she first started her treatment. We assumed this was just part of her cancer treatment and were only ever told it was to prevent infection.
64. Later in the year, around September or October 2019, ██████ was then prescribed Ciprofloxacin. ██████ was an out-patient but had been admitted due to a temperature spike. I'd had a conversation with Professor Gibson and the Infection Control doctor and was told to my face that everything was fine. By this time there were things appearing in the news but the next day, I was told by other parents via social media that all the children were being put on a new medication. I phoned the hospital and asked about the new medication as ██████ had been in the day before and we were told everything was fine. I asked why I wasn't told about the new medication when we were in the hospital the day before. I was told that ██████ would get started on it when she came to clinic on the Tuesday. I explained that I had just been in and was told everything was fine and I asked why they lied to my face. They said they didn't lie but that there had been a meeting later on that day and it was decided then. I said that they must have known something was going on for them to have that meeting in the first place.
65. When ██████ was at the clinic on the Tuesday, she did get put on the Ciprofloxacin. We were told by the doctors that it was to prevent the risk of infections. ██████ was only on it for a short time, not as long as the other kids. She didn't have a line and it was more the kids with a line and port it was for as they were at higher risk of infections due to things being pushed through their lines. That was all the information I was given by the hospital but one of the mums whose child had been in America said she was told the kids were on it because of the dirty water at the hospital.

## **OTHER ISSUES RELATING TO THE HOSPITAL CONSTRUCTION**

### **Hospital Build issues: Impact of construction works**

66. When they were working on the children's cancer ward and it had moved to the adult hospital, I used to worry if something happened to [REDACTED] en route. It was quite a bit away from the RHC and there were no electric doors so you had to hold the doors open. You also had to go in lifts with the general public to get to the ward. It was at least five minutes away.
67. More and more rooms started getting closed on the ward and we got machines in the room. I was told they were for the ventilation as it wasn't working properly. I didn't think this was right for a children's cancer ward and they should've found a ward more suitable for the children.
68. I asked why we were getting moved around rooms. I asked if it was safe and said that I wanted to speak to someone. Professor Gibson came to see me with an Infection Control Doctor but I can't remember her name.
69. Between August and October 2019 I noticed the rooms being closed off and we were being moved. We knew things were going on and knew the nurses were not happy either. The nurses would tell me that they were not allowed to tell us anything, but we would also get different stories from different nurses. They weren't happy about working there. We would be told that rooms were getting painted so we had to move, or the showers were leaking etc. I would ask why are there workers there in the middle of the night, why are they in the ceiling and on ladders etc? But no one ever answered me. I asked nurses and doctors but no one told us anything. The nurses wanted to be back at Yorkhill because it was a children's hospital. They didn't want to be in the adult hospital.

## **CLEANLINESS**

70. When Covid hit, we weren't allowed up to ward 6A until we had a negative Covid test so we would wait in the Clinical Decision Unit (CDU). It was disgusting in CDU. The cleaning wasn't up to scratch at all. I would ask for wipes and wipe everything down. CDU clearly didn't have the strict cleaning

protocols that children with cancer required to help keep them safe. We were never put back to ward 6A when covid was at its worst, because 6A was for children starting treatment so we were placed in other areas which was scary as we didn't know what risks we were being exposed to.

71. On ward 6A, we would hope we got a filtered room as they were cleaner.

## **OVERALL EMOTIONAL IMPACT ON [REDACTED] AND HER FAMILY**

### **Overall emotional impact on [REDACTED]**

72. [REDACTED] has a lot of mental health problems because of what went on at the hospital and from being in source. She also has a lot of problems with her physical health, with her bones and her head because of the clot. She still has a lot going on and is up and down constantly. I think this is also due to the amount of time she was stuck in her room in isolation too. She's still attending the hospital and is taking part in some of the activities she used to do before, like swimming and going on her bike. [REDACTED] loves football but she can't really play it because of her bones. She's hurt her ankle with kicking the ball and she's very weak on her legs.

73. [REDACTED] also has Avascular Necrosis (AVN) and she struggles to walk with that. She will walk for a wee while then she will have to go and sit down. These are more impacts of the whole treatment though. Her leg healed really well after the infection, eventually, but it's the psychology side of that; she's struggling with the scars. The scars could've been prevented. She's got scars up her side which are stretched from when she's been growing. The scars on her side and the one on her leg aren't nice. She doesn't have lasting physical effects from the scars. But psychologically she is struggling with the scars and up her side. It has stretched as she has grown and it is not nice for her. It could have been prevented because if they had dealt with it at the start it wouldn't have got to the point that it did.

### **Overall emotional impact on the witness**



74. My marriage broke down. [REDACTED] was more likely to let the doctors get on with things. He's very laid back and trusted them, whereas I didn't. I didn't trust them at all. Too many mistakes were made with [REDACTED] and it made me not trust. I trusted Professor Gibson but anyone else, I didn't trust.

### **Overall emotional impact on the family**

75. My elder boy hated seeing his sister so unwell and it affected his mental health. My younger boy has had no quality of life. None.

### **COMMUNICATION: GENERAL**

76. When [REDACTED] was first diagnosed with ALL, we were told she had ALL and that we would be moving to the Cancer Ward in the adult hospital. We weren't told anything else. Nobody came and told us anything, we were just left to it. When we moved to the ward, we didn't know what to expect then we saw all the children with bald heads, hooked up to drips through the windows. That's when it hit us that [REDACTED] had cancer. We hadn't even told [REDACTED] she had cancer yet as we didn't know anything about leukaemia, or the treatment. We didn't know what to tell her and had been wanting to find out more information first before telling her.

77. When I said to staff that [REDACTED] wasn't right. they didn't listen to me. When she had the infections, they didn't tell me anything. I had to ask loads of questions and at one point, a doctor told me I asked too many questions. When [REDACTED] was ill and I asked what was wrong, when they didn't know they would just tell me she was a medical mystery. We were left in the dark a lot of the time not knowing what was going on.

78. When Professor Gibson brought the Infection Control Doctor to speak to me, I felt that the doctor lied to my face. She told me everything was fine but the next day all the children were being put on antibiotics.

79. I remember there being a meeting round about Christmas time 2019 and it was in the building opposite the hospital. There were quite a few people there and there were people that worked at the hospital, including the Head Nurse, talking to us about the water but they wouldn't answer our questions. Every time we asked a question, they would twist it and wouldn't answer us properly.

80. We've had ongoing contact with the hospital but there's never been any communication about what was happening there. There's been no improvement in the communication since we were in with [REDACTED].

81. People were left worried sick about their child and the environment they were living in. We were getting information in the newspaper before we got information from the hospital. We would ask about the news articles and would be spoken to like the papers were exaggerating. It was a big worry.

82. I haven't noticed any significant improvements with how the hospital communicate with parents about the issues even today.

## **COMPLAINTS**

83. I complained to the nurses when [REDACTED] had the infection due to the cannula being put in and left for too long without being used.

84. When [REDACTED] had the infection in her leg and the plastics surgeons said it shouldn't have happened, we complained about it to every doctor in there. We made the complaint verbally to a lot of people and they made Dr Cozens apologise but we didn't feel an apology was good enough. We asked that he didn't treat [REDACTED] again. We were told however, that if he was the doctor on call at weekends for example, it would have to be him that dealt with [REDACTED]. I was actually pulled into a room and told by Professor Gibson and another nurse that I was making Dr Cozens nervous. I said I didn't care if I was making him nervous; my daughter could have died because of his negligence.

We are still deciding whether to make a formal complaint about this. We weren't in the right place to take it further at the time as our main concern was [REDACTED]. I think the plastic surgeons made their own complaint about it all though as they weren't happy with what happened to [REDACTED].

### **OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS**

85. I asked if [REDACTED] was included in the Case Note Review but I was told she wasn't. I really thought the infection in her leg would have been part of this though. I'm also not convinced that she should be excluded. They didn't know what the infection was in her leg. If they can't confirm that it wasn't an environmental infection, then I'm not convinced it should be automatically excluded.

86. I was a member of the Facebook Group that the hospital had set up and a group for the parents. I didn't find that particularly helpful. I didn't have any contact with Professor White.

### **CONCLUDING COMMENTS**

87. We applied for [REDACTED] medical records but there are bits missing from them. When she had that really bad infection in her leg, I remember seeing sepsis written on a piece of paper but it's not mentioned in [REDACTED] notes. I think there is loads missing from her notes. There would be a bit written about blood cultures being done but no lab results in the records. For the length of time [REDACTED] was in and all that happened to her with the infections, I was expecting there to be more written in her notes.

88. Professor Gibson is a wonderful woman. She helped me a lot with [REDACTED] and she came in on her own time to check on her. She still keeps a check on [REDACTED] as her ALL doesn't present the same way as others.

89. I would be concerned if [REDACTED] was to relapse as she would have to go through the treatment again in that ward.

90. I don't feel the hospital is safe. I don't think it is fit for purpose for kids to be honest. I don't think they should have mixed kids in with adults. A kid cancer ward should not be up in an adult part of the hospital where we're having to walk through all different corridors and different parts of the hospital. You're with people you don't know and you don't know what's happening on other wards. We're having to share lifts too. We had to fight to get a lift made for the ward which did happen, through Covid too. But you're still having to go into the hospital and mix with everyone that's at the bottom floor to then go up and use that lift. I remember one time when there I saw faeces on the floor outside a lift on a landing, it was disgusting, nothing was clean.

91. If the children's ward opens back up and it's done properly using the proper stuff to get it up to scratch, then maybe they could address the issues with the ward. But to be fair, I don't think a kids' cancer ward should be in that hospital at all.

92. 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.