Scottish Hospital Inquiry

Witness Statement of

Alfie Rawson

WITNESS DETAILS

1. My name is Alfie James Rawson. I was born on [redacted]. I am [redacted] years old. [redacted].

2. I am the father of [redacted]. [redacted] date of birth is [redacted]. She is 5 years old.

3. I live with my partner, Charmaine and our four children, [redacted], in [redacted].

4. I have a background in Health and Safety. I worked for 25 years in the Health and Social Care sector where I worked in a number of positions from Care Worker right through to being a Regional Manager. I then moved to Health and Safety within the Health and Social Care sector. Within my role in Health and Safety I worked in nursing homes, residential and leasehold properties where I would carry out inspections, fire risk assessments and deal with daily Health and Safety queries raised by staff members or management teams. I travelled all over the UK with this job.

OVERVIEW

5. My daughter is [redacted]. [redacted] was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in August 2018 when she was two and a half years old. [redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between August 2018 and November

2019 when she finished her treatment. She attended both hospitals as an in-patient and an out-patient regularly for just over a year. At present, while [redacted] does have check-ups they are few and far between and often Charmaine has to chase them up for ongoing medical matters for [redacted].

6. I have provided the Inquiry with a timeline showing the dates on which [redacted] attended hospital and the wards where she was treated. Charmaine and Thompsons Solicitors prepared the timeline. The timeline is attached to this statement at appendix 1 (**AR/01**) and in so far as I am able, I confirm that it is accurate to the best of my recollection. Charmaine is better placed to speak to the detail of the timeline.

7. [redacted] spent time in ward 2A of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children with blood cancer. [redacted] also spent time in another children's ward, 3B of the RHC. Following the closure of the Schiehallion Unit in 2018, [redacted] was treated in ward 6A of the QEUH. [redacted]'s mother spent 100% of her time with [redacted] at the hospital while I was at home looking after our other children. I visited [redacted] and her mother in the hospital on a regular basis and stayed over-night with [redacted] on ward 2A at around the time she was first admitted. I can speak to the experience which [redacted] and I had on these wards.

8. There are some specific events that I would like to mention. [redacted] contracted a Staphylococcus Aureus Infection in September 2018 just before the move to the adult hospital. During her time at the hospital, she contracted other infections too. I believe that [redacted] was prescribed preventative antibiotics in August 2018 which may have been connected to issues with the water supply. There were all sorts of issues with the hospital through-out [redacted]'s time there which, in my view, impacted her experience. I will come on to talk about these in more detail.

FAMILY BACKGROUND

9. I live with my partner Charmaine and our four children in [redacted] .[redacted] is [redacted] years old, [redacted] is [redacted] years old, [redacted] is [redacted] years old and [redacted] is [redacted] years old.

10. [redacted] started nursery on [redacted] and is [redacted]. [redacted], out of all the girls, is the softest, most loving, thoughtful wee thing. As much as she's been through a hard time herself, she always made time to have her wee sister in bed with her. She would try and interact as much as she could with as she's her best friend. [redacted] is a loving, gentle wee girl.

11. As a family, we like to go to the park around the corner from us. We were there this morning feeding the swans and playing in the park. A lot of the time now is spent on holidays. We try and spend as much time as we can together whereas previously I just worked continuously in every job I had. Now, our focus has changed. It's not about having the money; the money means nothing if you can't share it with the people you want to.

12. Prior to [redacted]'s diagnosis, she was a healthy child and was never unwell.

13. [redacted] was only about [redacted]months old when [redacted] was diagnosed. was [redacted]years old and [redacted] was[redacted] years old. [redacted] was just about to [redacted] . Charmaine was with [redacted] 100% of the time during the whole treatment process. I brought [redacted] and the other girls to see them. Usually in the mornings, I would get them ready for school or nursery and drop them off. I would then go home to get clothing prepared and lunches made up to take to Charmaine and [redacted]. They were fleeting visits sometimes. Charmaine was still breast feeding so I was picking up milk from her at the

hospital and then I would go and pick the other kids up to take them home, feed them and go back up to the hospital afterwards. I was taking [redacted] in so Charmaine could see her and try to get a bond with her but sometimes that was too difficult with everything that was going on. [redacted] would be unwell and needed attention. Nurses were coming in and out of the room all the time so there was no privacy to chat to each other. There were days where I would choose not to visit because emotionally it was extremely difficult for everyone so I would try and spend more time with the kids at home and I would maybe go to the hospital at night.

14. The first two months, I was trying to be at the hospital every day and spend as much time as I could with [redacted] and Charmaine. My neighbour would sometimes pick [redacted] up from nursery and [redacted] could go to a neighbour's house so I could spend more time with [redacted] but also so that [redacted] could spend more time with Charmaine. During [redacted]'s first admission I was at the hospital most days.

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

Admission to hospital: April 2018 – October 2018

15. On 15 August 2018, Charmaine took [redacted] to the GP. She saw a locum GP who told Charmaine that [redacted] had a viral infection. Two days passed and Charmaine took her back to see the family doctor on 17 August 2018 who examined her and said her lymph nodes were raised. He told Charmaine that his son had a viral infection as well and to expect [redacted] to be a wee bit sicker over the weekend. On the Saturday, [redacted] was really uncomfortable and on the Sunday, she was screaming in pain. Charmaine took [redacted] to the out of hours at Gartnavel Hospital, around about 6pm, possibly later. Charmaine then sent me a text message to say that the doctor wanted her to go up to the Sick Kids (RHC). Charmaine took her there and again, they said it was viral. Charmaine wanted blood tests carried out and that took a while. She called me later in the

evening to say it was leukaemia and we were to meet Professor Gibson the next day.

16. We both attended the meeting with Professor Gibson but for me, it was all a blur. I sat in tears and Professor Gibson was rhyming off everything [redacted] would be going through. For me, that was the worst day of my life, ever. I couldn't take any of it in. Initially we were told they would see how the first week went and if she made it, they would start her on a list of treatments. For the first few days, it didn't really sink in with me. During the first week, Charmaine stayed with [redacted] and I looked after our other girls.

17. If I remember correctly, [redacted] had surgery on 24 August 2018 to fit her central line. She was given a Hickman line. [redacted] then started her chemotherapy on 25 August 2018.

18. Charmaine kept a diary for herself and [redacted], to record the experience. Initially, she was trying to monitor and understand the whole thing about cancer. When the doctors came in and spoke about white blood counts and haemoglobin, Charmaine tried to understand it. If [redacted] had a blood test, Charmaine would ask for the numbers to measure where [redacted] was sitting. She did a lot of research during [redacted]'s treatment to try and get an understanding of what she was going through, what medications she was getting, what side effects they would give her and what her blood counts meant.

Experience on ward 2A: August 2018 – late 2018

19. I stayed over on ward 2A for one night near the beginning of [redacted]'s treatment. I think it was a Saturday night. Charmaine was finding it too much. When she did get home, she was finding it even more intense. She was surrounded by [redacted]'s stuff and she couldn't bear to be away from her.

20. Ward 2A was a quiet ward, very quiet. Lots of kids were in isolation or ‘source’ as they call it. They had signs on their room doors. The play room was pretty much empty at times.

21. Nearly every kid in ward 2A had an infection or was in ‘source’. There would maybe be one or two children walking up and down the ward or in the playroom. Other than that, they were all in their rooms with signs on their doors saying you had to check with a member of staff before entering. There was heavy scrubbed alcohol wash on every door too.

22. [redacted] was in source on ward 2A because of the infection she had in her line. Her having diarrhoea too, meant that she was often in source. Sometimes she would be in source for ages, possibly weeks. I can’t remember what was causing the diarrhoea but Charmaine can tell you.

23. I only really had direct contact with the staff the night I stayed over. Most of the time I was at the hospital, the nurses would be in doing [redacted]’s observations, taking blood or giving her medication. The same happened during the night that I stayed. Nurses came in to change her nappy but I was awake so I told them I would do it. They did her bloods, checked her temperature and her heart rate. I found it really bizarre though that they wrote the results down on what I thought was a piece of kitchen roll and put it in their pockets. If nurses are in several rooms during their shift, how do they know who’s result belongs to who? I assumed they were being put into [redacted]’s notes.

24. In my view, the note keeping in her medical records was pathetic. I have looked back through [redacted]’s records. I saw a note from early on in which the staff nurse had taken it upon herself to write that I might need social work intervention for further support. Now, there’s two ways of looking at this. It could have been well-meaning which I dare say it was. They might have wanted to check to see if I needed any support. From my perspective, I do not think that should have been getting jotted down in [redacted]’s notes. The notes were there for my kid’s health and wellbeing so the next member of staff could

see how my daughter's day had been, how her observations had been, what her temperament was, the medications she's had, what her eating has been like, her fluid input and output, her bowel movements and urine levels, not "does dad need support?". If I had needed support, I would have asked for it.

25. The ward protocols would differ depending upon who was on duty. Some of the nurses would adhere to them and some would happily turn a blind eye and get on with their shift.

Facilities on ward 2A

26. There was a playroom in ward 2A. [redacted]'s siblings came to visit but Infection Prevention Control wouldn't allow [redacted]'s siblings into the playroom. Kids being kids, [redacted] would want to go into the playroom but how do you tell her that her siblings can't go in with her? How do you say to her and her sisters, you can go in but you can't? We'd remove our kids but on occasion, other families would be allowed to have their kids in the playroom including the siblings. It was inconsistent depending who was on duty.

27. There was a parent's kitchen on ward 2A. If I was there, I would use it to make Charmaine and I a cup of coffee. It had microwaves, two fridges and a seating area where parents could go and have a seat and a coffee. One of the charities would bring in snacks for the kids and the adults.

Closure of ward 2A and the move to the adult hospital: Late 2018

28. I was not present during the move itself. I went up to visit Charmaine and [redacted] later on in the day and they were in ward 6A.

29. With the reports being in the media though and the hospital starting to move the kids to ward 6A, it became so obvious that they were moving because of infections. They were dousing the taps and the hand-wash basins. Looking

back in hindsight, I should have noticed all of this considering what I was doing for a living. It was all in plain sight.

Experience in the QEUH (adult hospital): late 2018 – September 2019

30. Ward 6A was split in two. If you come out the elevator there are two double doors then you would see four rooms then the nurses station. If you turned right, that would take you to another wing of 6A with maybe ten rooms there. At the top of that, there would be Day Care and the rooms in Day Care. The rest of the rooms would be after the nurses' station.

31. There was absolutely nothing for the kids in ward 6A. It wasn't fit for purpose. Kids would be in their rooms, in source, as they called it. The odd kid that wasn't in source, would sit in the corridor in a makeshift play area which consisted of a chair with a wee plastic table with a couple of bits of blank paper and maybe a couple of pens. That was to entertain them. That was what they classed as a play area. It was placed at the big entrance between Day Care and the nurses' station. You would have to walk past it to get to Day Care which did not make sense for infection control.

32. When [redacted] wasn't in source, our source of entertainment would be walking around the ward as it was split in two so we would walk up and down. would look into the rooms to see her friends and we'd maybe play hide and seek. During the day, they had the clown doctors for entertainment. Maybe one of the charities would come and do a bit of entertainment with the kids. Sometimes they would maybe get toys in but it was a pretty dark experience.

33. There were no facilities in ward 6A for making food or heating anything up either. Usually, if I was visiting, I would stop off downstairs and get a coffee or maybe soup and a sandwich for [redacted] and Charmaine. I often took them dinner in and I did this through-out. If [redacted] or Charmaine wanted anything heated up, I had to go downstairs to the main atrium where there was a microwave next to a vending machine. Anybody could use it; it was in a public area.

34. I was taking meals into Charmaine and [redacted]. I did this when they were in ward 2A and 6A. The food I was preparing at home was better than what they were getting in the hospital.

WATER: EVENTS INVOLVING WATER SYSTEMS

35. There were signs up in the parent's kitchen above the sink saying 'not drinking water' and there were loads of bottles of water. Initially when we were in ward 2A, you had to ask staff to get you a bottle of water but you had to wait until they had time. We were not allowed to drink the water in the room and there were no jugs of water. I remember when you used to visit someone in hospital and there would be a jug of water in the room in the morning, it would get changed in the afternoon and again in the evening. There was nothing like that here. There were signs in the bedroom too telling you it wasn't drinking water, it was for hand washing only.

36. I had a shower when I stayed over but [redacted] was always wiped down with baby wipes as after the two or three times she did have a shower she had an infection afterwards.

37. The situation was the same on 6A as it was on 2A. You were offered bottled water and there were signs up saying the water was not for drinking.

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

38. [redacted] had to have her line removed on 23 September 2018. I think she had a temperature and had taken unwell. Staff came in and took swabs of the site where her line was and they took blood samples from her line. I think the infection was a staph infection, Staphylococcus Aureus.

39. The impact of the staph infection on [redacted] was that her treatment was stopped. Staff had put a pause on it and they also had to revert back to cannulas. They removed her line under general anaesthetic in surgery and they reverted to cannulas. Staff couldn't always get the cannulas into [redacted]. On one occasion I was there and the staff tried 10 or 12 times to get the cannula in to [redacted]. We said no more, stop. It was so traumatic for Charmaine, me and of course [redacted]. Charmaine saw all of this. On occasion I would see this if I was visiting, but Charmaine saw most of this.

40. On another occasion, [redacted] developed marks on her legs. The dermatology specialist came to visit her and put circles round the marks and told us it was a fungal infection. Someone from microbiology came down to take samples. The next day or so, Professor Gibson arrived to say it wasn't a fungal infection. Before dermatology had visited, Professor Gibson said it was bruises from falls but [redacted] was pretty much bedbound so hadn't fallen. What she said didn't really make any sense. As far as I can remember, they said that someone from microbiology would come and speak to Charmaine but she was still waiting on the results and is still waiting on someone coming to speak to her to this day.

41. On 21 January 2019, [redacted] had a fever so was admitted again. She was placed on Ambisome and other medications. Charmaine is good at all this stuff. I only know a couple of the drugs, Methotrexate, antifungals and antibiotics, Charmaine was at the heart of this so knows it all.

42. I think the infections are related to the construction. It must have had an impact or they wouldn't have shut it and spent £14 million on water and ventilation systems. So yes, I think this has had a real impact on her.

HAIs: communication

43. I was not there when staff discussed the staph infection. Charmaine would be the best one to confirm this as she kept track of everything. She spoke to the staff about it.

PREVENTATIVE MEDICATION

44. I do not know if [redacted] was on preventative medication. Charmaine is the best one to answer this. I knew a couple of the names of medicine [redacted] was on but not them all. Charmaine did a lot of research to understand what medications our daughter was getting, why she was getting it and what it would do to her. I can't fault her for that. She looked after our daughter 100%.

CLEANLINESS

45. On one occasion when [redacted] was first admitted to ward 2A, she'd been there maybe a couple of days and I'd taken her a new doll up. It was in the usual packaging, cardboard and plastic. [redacted] was excited as she had lots of dolls and we took the new one out of the packaging for her. She wanted to go and play in one of the wee play areas that was set up so we were in there playing. [redacted]'s room was next to the nurse's station and we saw four nurses going into the room, stripping the bed and picking up all the packaging. When I say all the packaging, there was also a carrier bag as I had also bought new clothes for [redacted], new pyjamas and a couple of outfits. We went to speak to the nurses to ask what they were doing and we were told this wasn't allowed because of infection prevention control measures. I thought this was bizarre. There were two bins in the room, if they'd given me a moment, I'd have put the packaging in the bins but on that token, nurses go overboard with things like that but the same nurses would be happy to leave 14 bedpans in the room with faeces in them. It was really bizarre.

46. The incident with the 14 bedpans happened during the first couple of weeks when [redacted] was admitted. She had really bad diarrhoea and we were to take samples to monitor how many bowel movements she was having. I had visited and went into the bathroom and there were all these bed pans sitting. I asked Charmaine how she was managing to sit in the room with those being left. She had been waiting for staff to come and collect them. The bedpans had been

there two or three days. They were all you could smell, every time you opened the bathroom door. I spoke to a member of the nursing staff to ask if they could be removed and they said they would get round to it. Nursing staff said this quite a lot. If there was a trainee nurse or a student, they would come and collect them.

47. There was the odd occasion where getting a bed sheet was very difficult. It got to the point where I took [redacted]'s own. I bought [redacted] a new quilt cover, and bedding. The only thing that was supplied from the hospital was the bottom sheet. I used to take her bedding home, wash it and bring fresh bedding in for her. The hospital didn't provide the bedding quick enough. I was taking bedding home to wash daily, sometimes a couple of times a day if her nappy had leaked bearing in mind she had diarrhoea, or if nurses had taken blood as sometimes there would be blood on her bedsheets.

48. The cleaning process for the rooms on the ward was very sporadic. The task the cleaners were carrying out could be random. Rather than clean a whole room, one cleaner would come in, maybe about 11:00 AM and dust the room then maybe an hour or so later, another cleaner would come in and mop the floor. I did not see the purpose of the cleaning being done in this way.

49. On ward 2A there were people who I presumed were contractors, who came in to douse the drains. The kids would be moved from one room into another room and then plastic sheeting would go up to allow the contractors to do their work. I'm not too sure what they were dousing the drains with. The people doing this did not have any protective clothing on, just overalls which made me think they were contractors rather than in-house maintenance staff. They doused the drains in the bathroom, the bathroom sinks, the wash hand basins in the rooms and the showers too I think. The furniture was kept in the room and a cleaning team would go in and disinfect the mattress, the bedframe and the furniture. The room was cleaned from top to bottom.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

50. I noticed in ward 2A, that there was a team of painters who would just go around painting. This surprised me for such a new building. It was not to just to keep up with the décor, it was to cover over cracks. When you saw one, you thought they were maybe just touching up paint work after builders had been in but the more you sit in that environment, the more you see. The rooms that had been in, there were cracks all over the walls.

51. On the outside of the building, they were taking off the cladding. This had me thinking, because of what I used to do in Health and Safety, about Grenfell. They were taking off the cladding and removing insulation to put in Rockwool. The difference being, one is flammable, and one is a fire stop. It had me thinking, was the hospital actually fit if there was to be a fire. Rockwool is an insulation but it buys you time should there be a fire. I think it was in 2019 that they were removing the cladding.

52. The temperature in the rooms was roasting, the same as the rest of the hospital. You were unable to open the windows and doors and there was nowhere to turn the heat down. I do not know if the temperature was controlled centrally.

53. I witnessed windows popping out when I was at the hospital. There was one which fell out at the Bute or Arran side of the QEUH, I can't remember what that part is called. There were a few windows that popped out of there as well. I think at least four or five windows fell out.

54. There was a smell at the hospital, well more than a just a smell. Considering there's a sewage plant 1000-2000 feet away, when that gets churned up, you're not only smelling it, you can taste it and the smell is in the hospital.

55. I believe kitchen facilities have been put in ward 6A for parents now. I haven't seen them; they were getting installed as [redacted] was finishing her treatment. The kitchen was being put in at the entrance of ward 6A just through the door. They turned a storage room into the kitchen.

56. They've also changed the food on offer for the kids too and there's somewhere for them to go on that ward now I believe.

COMMUNICATION ABOUT BUILDING ISSUES

57. I was concerned that we were not being told what was going on with the building. I started looking into the construction of the hospital and the water supply. When I started looking in to it, I found out that before the hospital opened, people were aware that some places were not fit for purpose. I say that because there were transplant patients transferred to the hospital in, I think July 2015, but by the August 2015, they'd been sent back. This was due to the ventilation system but the hospital were well aware of the issues. I think that the issue with the ventilation system was that it was installed back to front. I found out information through reading reports online.

58. When it came out in the media that there were issues with the water, I wanted to see what the Dispatches water report said. I read some stories in the media and managed to find some news reports online. I have also asked for reports on the water samplings. I wanted to see for myself what had been going on at the hospital. I knew that there would be water reports because in my previous job working in Health and Safety at a nursing home we had staff working on a monthly rota. You would take one shower head off and replace it, disinfect the other one and swap it over every month. I wanted to see the hospital's record keeping.

59. I asked for the raw data on water sampling reports 18 months ago through Professor White. Initially I was told they were going to break it down to laymen's terms for me so I can read it but I am still waiting for it.

60. I recall attending a meeting at the hospital, when they said they had doused the water with chlorine dioxide while simultaneously maintaining the position that the water was meant to be wholesome. I do not know how water can be reported as being wholesome when they found 23 pathogens in it and some are growing fungus. This was on a slide at the meeting we attended. I've looked at the Healthcare Improvement Scotland reports online from 2018 and as far back as 2015 where it states water sampling was carried out before the hospital was open. That sampling was commissioned by the NHS GGC Health Board. That report has not seen the light of day. It was supposedly never reported to the head of the NHS or the Scottish Government. I have looked at the reports within Healthcare Improvement Scotland. The water issues were looked at and covered in 2018; there were also 11 patients with different types of infections. Those water samplings and the 23 pathogens in the water, ranging from staphylococcus to two different types of pseudomonas. In 2015, when the water sampling was carried out, and again in 2017 and 2018, actions that were required were not taken. In some of those reports, Legionella was mentioned.

61. Having seen these reports, I'm interested in finding out what the raw data shows. I would like to know if the sampling and testing was carried out in-house or if it was external. There is a main contractor I know of that the councils use. I want to know who was doing the sampling, and the microbiology testing. Why did they have to take steps to douse the water if the water coming into the hospital was wholesome? That would indicate that between the inlet and the outlet, there's an issue. Bacteria is growing somewhere.

62. Everything I've mentioned here is freely available information. It led me to ask my own questions to get answers for [redacted].

63. Throughout the whole process, we were asking questions, why can't we bath our kids, why can't they drink the water out of the tap and we were told nothing

was wrong. You asked the Health Board and they tell you nothing is wrong yet after a meeting with the Health Secretary three or four weeks later, you're invited to a meeting with the heads of the NHS.

64. There was a meeting with Jeane Freeman held in the Central Hotel in Glasgow. I went to that one. I thought it was lip service. We had a Health Minister who was trying to show she was empathetic and she tried to convey that she was unaware of what was going on but she's seen these documents that were released to the Scottish Press. I think she was aware of professional concerns and she chose to ignore them along with the Health Minister before her. The Scottish Government as a whole chose to turn a blind eye. She's the Health Minister, if she wasn't aware of all of this, then she isn't doing her job properly. If you have a Health Board that isn't passing critical data to the Health Minister then surely that Health Board shouldn't be in place.

65. What I have found during this process, even in Inquiries, these people are actually policing themselves. For example the report that Jane Grant commissioned before the hospital opened, never reached the Government. They state that they have never read the report, yet they commissioned it. I do have faith in this Inquiry that they will investigate things properly.

66. Three to four weeks after the meeting with Jeane Freeman, we were invited to attend another meeting with NHS GGC. I can't remember the exact date of this meeting but I do remember it being a Saturday morning at 10 am. A male nurse whose name I cannot recall, Jane Grant and the Head of Nursing were there. In total there were nine professionals from the hospital/Government that were in attendance. There were maybe six or seven of the bosses from NHS GGC who attended. They wanted to apologise for any distress caused by the lack of communication. There were maybe around 15 families there. They reiterated there was nothing wrong with the water. They kept using the word wholesome that was the word of the day. They said none of the infections were related to the water but they admitted they should have been better at communicating with us. They said they recognised this and were going to act

on it. I don't know when they are going to act on it as they still do not interact with us or communicate with us very well.

67. I thought what was said at the meeting was just lip service and I felt it was backhanded. At no point were that set of people, unless told otherwise, getting out of their beds on a Saturday morning to hold a meeting at 10 am unless they were told to by the Scottish Government to make it happen. They didn't hold the meeting of their own free will.

COMMUNICATION GENERAL

68. When I asked why they were dousing the drains, the nursing staff told me it was just part of the cleaning process. When [redacted] was being moved rooms due to this, we were only given about an hours' notice.

69. I can't remember exactly how many times she was moved but she was moved several times within ward 2A.

70. I found out about the closure of ward 2A via the media. I had a friend who sent me a text message asking if I had seen the news. The media were reporting that ward 2A was being closed and that the kids would all be getting moved. I went to the hospital and Charmaine told me there was a letter to say they would be moving. I can't remember exactly what the letter said but it was on an A4 sheet of paper and it had been placed through the door. We were not told why ward 2A was closing and the kids were getting moved.

71. We attended a meeting where the facilities manager stated that everything would be moved back to ward 2A in spring 2020. To date, they have spent in excess of £14 million trying to fix ward 2A plumbing and ventilation. The same male nurse whose name I cannot recall said it was the Rolls Royce of ventilation that was being put in. If they were putting that in now, what were they taking out? Again regarding the plumbing, if they're putting in the best

plumbing, what did they take out? All this yet we were told there weren't any issues in ward 2A.

72. I found out about the Cryptococcus that was related to the pigeon droppings, in the media. I think this was in the December of 2018. Like everything else regarding the hospital, everything is second or third hand. Parents were never told of this until it got so much exposure in the media that they released a statement. They said that two patients had caught Cryptococcus virus and this was through pigeon droppings. They didn't say where about in the hospital this had happened, only that it was an adult and child patient. There are only two places in the hospital that this could've been though and one of those places was ward 6A. There were adults on ward 6A and 6B as this was an adult ward too.

73. If it had not been for the media, we would not have known about the issues. Everything from the hospital has been relayed to us second hand. They couldn't tell us why our kids were moving rooms, they couldn't tell us why our kids were moving wards and when you ask a question, you get stonewalled by either staff, Professor Gibson or maybe hospital management. I don't expect a nurse to tell me what's going on; that is above their paygrade and I don't mean that in a derogatory way but that's not part of their job. It's the same for Professor Gibson, she's there to be the best doctor she can be. She doesn't get paid to carry the can for her bosses. Not for one minute will you hear any of the families criticise the way our kids have been looked after; they've saved our kids' lives. It's the environment and the management.

74. On 24 December 2018, Professor Gibson asked us to attend a meeting. I had posted on my own social media that [redacted] was now a guinea-pig regarding her cannula. Someone had been trying to insert a cannula into [redacted] but it took 7 attempts. I was sick fed up of the treatment. It's my Facebook page and it is for my personal views. There were a couple of times we were 'called in front of the head master' for doing this. The hospital don't understand people's frustration. People get frustrated when their kids are going through treatment and there is

only so much you can watch your kid go through before you have to tell someone to stop something they're doing. I don't mean the treatment but if you are going to dawdle, and take your time with the treatment then you do it properly. Staff should not need 7 attempts to put a needle in and if they do, then maybe you shouldn't be doing that. I was asked by Professor Gibson not to put stuff like that on Facebook.

75. There was a meeting on 27 December 2018 to discuss [redacted]'s treatment plan. I attended that however, [redacted] was admitted to hospital again on Hogmanay. She had a fever but Charmaine knows all the details about this.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HER FAMILY

Overall emotional impact on [redacted].

76. [redacted] still sleeps with her Mum. She doesn't like being by herself. She's a scared little girl at times. I think the whole treatment she's had, people just coming in to her room at the hospital during the night, stabbing her with needles, pulling down her pyjama top to listen to her heart, rolling up her sleeves to take her blood pressure, all of this must have a horrible impact on her as a child. We are trying to teach her about her space and that it's her body. So yes, everything has had an impact on [redacted]. Even the water, she knows she can't use it. She's fine at home though and knows it's safe to take a bath there.

Overall emotional impact on witness

77. For me, every block of chemotherapy was difficult that was probably why Charmaine was better off being there 100% of the time. I can't watch things like that. I found it distressing even visiting. There was the odd day when [redacted] was really sick that I only lasted five minutes. She looked like a corpse. I walked in and walked out again. We didn't want her siblings seeing her like that. It's maybe selfish of me as Charmaine was sitting seeing [redacted] every day

like that but I just couldn't cope. There's times even now when she's unwell, even towards the end of her treatment, I always found it difficult. Nobody wants to see their child sick maybe to the extremity where I did visit [redacted] and she would be lying with blood coming out of her mouth or her backside was sore. That was just too much for me. Nurses not being able to get cannulas in, that became too much for me as well. On the times I was there when this happened, I'd tell them to stop. I know how it feels as an adult when the nurses can't get a needle in but for a kid, it must be so traumatising.

78. I think about how you can't protect your kids. Is there something more I could've done? I feel frustration, anger, a whole mix of feelings and baggage.

Overall emotional impact on family members

79. The whole experience has affected us as a family. It's had an impact on relationships. Our mental health has suffered.

80. The staff with Charmaine were intimidating. They would go into [redacted]'s room in twos, threes or sometimes fours when they spoke to her. It was overpowering and unnecessary. On one occasion when I was visiting, four nurses appeared in the room. Sometimes they would come in the room in twos, depending who was on duty.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

81. I was involved with the Oversight Board. They were looking for other parents to take part. Myself and another parent were the only parents that came forward. The meetings for it were held every two to three months. I only went to one or two meetings. I had to come out of it due to my own mental health. I had lots going on and I didn't think I would've done any of the other parents any justice so I stood away from it.

82. I was involved in the communications and engagement elements of the Oversight Board. I understand why the Oversight Board was set up but surely as an organisation who are meant to be patient focused and have a person centred approach, they shouldn't need outside people telling them how to engage with other people. Surely that should be at the forefront of person centred care delivery? They should know how to engage with the person receiving the treatment and how to engage with their family members. I've always thought, especially after having spent 25 years in Health and Social Care that the fundamental of care delivery is knowing how to engage with people.

83. I looked over the Oversight Board report but in my opinion, it's probably the biggest waste of time and money. They shouldn't have needed to do this if the people at the top of the organisation had filtered things down but I think the beast is too big. The hospital is too big to manage. The directive that's coming from the above, isn't being filtered down to those on the floor. It's getting lost somewhere in translation and it doesn't matter how many Oversight Boards you're going to have, if there's a break in the system, nothing will ever reach where it's meant to get to.

84. I stated at the meeting, there's too many bosses and not enough leaders. There's a lot of people who have their own agenda who are power driven. Where you have a leader, people will follow a leader rather than a boss. If people are shown how person centred care should be and how to engage with people, that example should filter through. It's like everything you do in life, everything is set by example and that's where leadership comes in.

85. I don't have anything else to say about the Oversight Board. I don't think I've got any room to say anything further due to my limited attendance but that's my view of it. There were three of these groups going on at the same time, one filtering into the other and it was all going up the chain. These groups are only as good as the person reading the end result and if there's no action taken, then nothing changes.

86. [redacted] was included in the Case Note Review. I've had no interaction with it though. I think we can take a lot from the Case Note Review, it showed we weren't paranoid parents which is how we were viewed by some other people. We're not trouble makers. We were right in everything we said and we are still right in everything we said.

87. We have [redacted]'s report from the Case Note Review. One of the infections named in it is pseudomonas. The results are all broken down into different groups. You've got "possible", "maybe", "definitely", things like that and throughout the report you can see that there's a trend in all different types of infection. As parents, we knew our kids were sick and we knew they would pick up infections but we did not expect our kids to pick up an infection in the place that was treating them. Nobody expects to go into an environment to make them better and not be allowed to wash. You're in hospital to rest, recuperate and get better. Fight for your life but you can't have a bath or a shower and you can't drink the water. What kind of environment is that?!

88. The communication from the Health Board is still as bad as it was at the beginning. Half of the reports came back saying 'maybe the infections were related to the hospital environment'. Maybe I live in a different world but if I was Jane Grant and this was sitting on my desk, it would have been a priority. There weren't a lot of individual reports considering who was getting a reply so surely you would take time out of your day to write a letter and sign it. You don't just send out a bog standard letter if you want to show empathy and compassion as she stated she has.

89. At the end of the Case Note Review, we got a letter. It was a corporate nonsense letter just saying they were sorry about any distress caused and that they were trying to make it right. They can keep it. I believe it was sent out to all the families.

90. I was a member of the Facebook group for parents. I came off it though. It was set up for parents to support each other. People who are going through the experience, or have just finished the experience. It was supposed to offer support. It was a support mechanism, a blanket, whatever way you want to describe it but it seemed it was being monitored. There would be comments made on it, people venting. It wasn't for me though. Charmaine may have used it more than I did, I'm not too sure. I never really took anything away from it. If you raised concerns on it, the staff would always be aware. I left the group.

91. I joined the Facebook group set up by NHS Greater Glasgow and Clyde ("NHS GGC"). "Every day is a good day" was the impression you got from the page. If there was a story in the media, you would get a response on the Facebook page. I didn't think it was very good for communication.

92. I had some communication with Professor White. If you had a question, you would raise it through Professor White and he would then find the right person to answer you and you'd get an answer that way. It wasn't an immediate response you got, hence why I am still waiting 18 months later for water reports. If it was an easy response that was required, you'd get a response but if it was a wee bit harder, you would wait until someone spins you a story. I asked for water reports, a couple of Health and Safety reports and maintenance records. To date, I've none of these. I also wanted to see the structure of the Senior Management. I wanted to see how big this organisation was and who the top management tier was in the hospital and how many managers feed in to it. When you start a new job, you get a staff handbook with an organisation chart that shows you who your boss is, who their boss is and who their boss's boss is. I just wanted an idea of for myself, how big the beast was.

CONCLUDING COMMENTS

93. The whole thing could have been handled a lot better. If they had been open and transparent from the start and said right from the beginning that there were

issues then parents would not have been in this situation. I understand that it is hard to admit there are issues when you've just spent £842 million on the state of the art hospital to find there are big issues. If they'd said at the start about the issues, they could have had them fixed in 2015 when they were first highlighted. It could've been like the Edinburgh Sick Kids where they just delayed the opening but the reason they couldn't do that is because they had already closed every hospital in Glasgow so there was nowhere to go. They'd already shut down the Sick Kids, the Western Infirmary, and parts of the Victoria Infirmary. I can understand why they didn't say anything but surely if they did and had been open and honest we wouldn't be where we are today. That goes for the Cryptococcus incident too. If they just give people the answers then parents wouldn't find themselves in this position.

94. It's too late to say rip the hospital up and start again. That ship has sailed. In relation to the hospital itself, I think someone has to go in with an open mind and be allowed to restructure things because the way it is just now, it's not working.

95. I think the Health Board has let us down. What they are doing is also letting the nursing teams down too. If they had known how to engage with people and be transparent then this wouldn't be the situation we're all in now.

96. I still have concerns about the hospital. I've watched it. When you see windows falling out, workmen taking off the cladding, new insulation being put in and cracks inside the hospital, of course you still have concerns.

97. 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 – TIMELINE (AR/01)

- 17th August 2018– [redacted] became unwell and Charmaine took her to the GP. The GP said that this was likely a viral infection. They went home but remained unwell and was very pale.
- 19th August 2018 – Charmaine takes [redacted] to A & E for further investigations at QEUH. She was transferred to CDU and late in the evening after blood tests were completed, the family were told that she likely had leukaemia. She was moved to ward 2A to room 7.
- 24th August 2018 – [redacted] has surgery to fit a Hickman line.
- 25th August 2018 – [redacted] starts block one of chemotherapy, there were multiple room moves during this time. [redacted] remained in ward 2A till the ward closed around the 26th of September 2018.
- 23rd September 2018 –[redacted] has a line infection. The line is stopped.
- 24th September 2018 – [redacted] has emergency surgery to remove the Hickman line.
- 1st week in October 2018 – [redacted] is discharged home for 3 or 4 days and was then readmitted.
- 11th November 2018– [redacted] is admitted to hospital to start her 2nd block of chemotherapy to ward 6A
- 12th November 2018 – 2nd block of chemotherapy commences.
- 17th November 2018 – [redacted] is discharged home.
- 22nd November 2018 - [redacted] is admitted to hospital because she is throwing up blood. She is admitted to ward 3B in the Children's Hospital. ..
- 26th November 2018 – [redacted] starts 3rd block of chemotherapy.
- 24th December 2018 – Meeting with Professor Gibson. [redacted] is discharged home.
- 27th December 2018 – A meeting is conducted in the hospital to discuss [redacted]'s treatment plan.
- 31st December 2018 – [redacted] admitted to hospital to ward 6A.
- 3rd January 2019 – [redacted] is discharged home after a lumbar puncture
- 21st January 2019 – [redacted] has a fever and is admitted to hospital.

- 23rd January 2019 – Put on Ambisome – infusion – she was put on this infusion every 2 days
- 31st January 2019 – Charmaine reports to a nurse that [redacted] has been itchy. No rash evident. (this is a note from [redacted]'s medical records)
- 20th February 2019 – [redacted] develops a staph infection. The line is not removed.
- 25th February 2019 – [redacted] is discharged home.
- 15th March 2019 – [redacted] had a blood transfusion at clinic
- 19th March 2019 – [redacted]'s temperature spiked and she was admitted. Blood cultures were taken
- 21st March 2019 – confirmed Pseudomonas diagnosis. [redacted] receives antibiotics for this until she recovered.
- 24th March 2019 – [redacted] develops little round circles on her knees. They looked like bruises.
- 25th March 2019 – Dermatologist examines this and confirms it is "Candida (a fungal infection)
- 25th March 2019 – She starts medication for this infection. Ambisome infusions 4 times a day and Antifungal medicine posaconozol
- 29th March 2019 – [redacted] is discharged.
- 1st April 2019 – Maintenance round of chemotherapy commences.
- 26th September 2019 [redacted] was admitted to ward 6A room 11 for 48 hours for a cold That was her last hospital admission at the QEUH.