Scottish Hospitals Inquiry

Witness Statement of

Sharon Barclay

WITNESS DETAILS

1. My name is Sharon Barclay. I was born on [redacted]. I am [redacted]years old. I am a [redacted].

2. I am the mother of patient, [redacted]. She is 7 years old.

3. I live with my partner,[redacted], and my two children,[redacted]. I have two older children who are now adults and don't live with us.

OVERVIEW

4. My daughter is [redacted]. She was diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in May 2017, on her third birthday.[redacted] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") between May 2017 and October 2020 when she finished her treatment.

5. [redacted] was treated in the RHC on ward 2A as in-patient and on 2B as an out-patient. We basically lived in 2A for the first 10 months. [redacted] was in 'source. This is when you have to stay in the bedroom, most of the time. She was also in ward 3 at one point, that's the ward for patients waiting for dialysis and transplants. She got put in there because there was no room on the unit. We were also in ward 6A in the QEUH for two nights but I don't know when that was. [redacted] treatment lasted for 28 months. I stayed with [redacted] for a lot of the

time, although I shared the care with [redacted] and her gran. I can speak to the experience that me and [redacted] had in the hospital.

FAMILY BACKGROUND

6. At home with my partner [redacted] and I are my two youngest children, [redacted], the youngest, and [redacted], who is [redacted] years old. [redacted] and [redacted], who do not live with us, are my oldest sons.

7. [redacted] has Down Syndrome and can't speak. I have to speak for her. She has been in and out of hospital since she was 17 weeks old. She had a large hole in in her heart and was rushed in to hospital for major surgery.
Dr McLeod saved her life that day. She also caught RSV at one point and nearly died. [redacted] was in and out of hospital for bronchitis where she would need oxygen for a while.

8. [redacted] is a very lively child. She is not yet in primary school and is not at nursery. She has been kept at home for another year with me. She will go to school next year. [redacted] really likes music. She has a typical sibling relationship with her brother [redacted] who has autism.

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

Admission to Hospital: May 2017

9. [redacted] had a viral infection for about three weeks before her third birthday. It wouldn't go away. We went to see our GP on 30 May 2017. Our GP is at Medical Centre and he referred us to the Queen Elizabeth University Hospital that same day. He sent us to the hospital to get [redacted] checked over.

10. Me and [redacted] took her to the hospital in Glasgow. She had an X-ray carried out and the doctor said everything looked okay and that we could go home. It was

a younger doctor who did the tests in the hospital. [redacted] had gone to get the car from the car park. Just as we were about to get in the car park, another doctor came running out and asked us to go back in. He told me that [redacted] had multiple fractures all over her body. He accused me of dropping [redacted] on her head. I asked [redacted] if [redacted] had fallen down the steps at his mum's house as I knew I hadn't dropped her. I asked the doctor where the fractures were and he wouldn't tell me so I asked to see the scan and we went back in to the hospital.

11. I have two older boys and they had broken bones when they were younger so I knew what they looked like on scans. There were no breaks showing on the scan. There were marks up at the head area. [redacted] has been a head banger since she was 6 months old. This is part of her Down Syndrome so it's possible she's had trauma from that. I do my best to make sure she doesn't do it but she won't stop. I have never, ever dropped her.

12. The hospital had taken other scans and I could see clouding all over [redacted]'s body and around her head. From my own research I was aware that this could be a sign of cancer. I asked Dr Danson straight away if [redacted] had cancer but he told me he couldn't confirm this as it wasn't his area. Dr Danson was a bone doctor.

13. On the same day, the 30 May 2017 he admitted [redacted] to ward 2A in the RHC, it is known as the Schiehallion Unit. She was in Bed 1 which is right next to the reception in the ward. At that stage I knew it was cancer, I knew that this was the child cancer unit. Lots of blood tests and DNA tests were performed over the next day and we stayed in overnight. Professor Gibson was the doctor on the ward. The next day we received the clinical diagnosis, [redacted] had acute lymphoblastic leukaemia ("ALL").

[redacted]’s initial treatment

14. [redacted] got lots of medications and treatments but I can’t remember all of the details or dates she got them. Professor Gibson told me that they would have to do an operation to get a central line into [redacted], then they would start chemotherapy and get all the medicines she would have to go on. I don’t know what type of central line she had at first, it was plastic and yellow and was fitted by surgery under a general anaesthetic. She got steroids and Ciprofloxacin.

15. [redacted] was in receipt of treatment for a total of 28 months and that was them shortening the treatment by six months because I was told that she would never be able to complete the chemotherapy because she wouldn’t be able to take the strongest dose. She was an in-patient and out-patient during this time.

16. During her first admission, [redacted] was an in-patient in ward 2A. She stayed in the hospital for about 10 months during that first admission.

Overall experience on Ward 2A

17. Nothing worked in ward 2A. I found it was either too hot or too cold to the point I could see her breath. I did not feel the ward was clean.

18. During the 10 months in the ward, I spent a fortune buying food from Marks and Spencers or would go without food for periods of time. I went from a size 12 to a size 4 with the stress of what was going on for [redacted] and then the stress of how the family were being treated. I developed an eating disorder. Microwave meals for [redacted] was also not an option. [redacted] was already going through cancer treatment so I didn’t want to irradiate her food on top of this. I felt that [redacted] should have been offered a healthier option to eat.

19. When [redacted] was in source, we weren't allowed to use the kitchen facilities, if you wanted anything, you'd have to ask them and they would bring it to you. Half the time I didn't ask for anything because you would wait forever. They don't offer the adults food in the hospital, just the children. The food was worse than prison food. [redacted] couldn't chew. She needed soft food. What they gave her was awful. It was brought in from somewhere, not prepared on site. It was pureed to death, broccoli and green things. It smelled awful and it was microwaved every time. My daughter was already going through cancer and to me, the food she was getting was radiation food as it was microwaved. It wasn't right. There was a new kitchen on the 3rd level of the hospital, it should have been used to prepare meals for these children but it never got used. I ended up shopping in Asda and brought my own food in all the time. It cost us £4,000 just living there for that 10 months. I wasn't offered food vouchers but some families had some. It wasn't just me and [redacted], there were my other children who also ended up living there in [redacted]'s room

20. Eventually [redacted] was put on TPN which was extremely difficult to manage as [redacted] wanted to pull out her feeding tube from her nose.

21. I was also concerned with the kitchen and the non-medical facilities like the playroom. People were mixing and there was very little infection control here. There was a protocol that only patients were to play in the playrooms, but I saw families with many siblings playing in the playroom. It was one rule for one family and a different rule for others. The cleaner used to come into the room and clean the bathroom and then clean the bedroom. I challenged this because there was a poster on the wall that said that the room was cleaned everyday for 45 minutes. They cleaned once a day. The only time the room was cleaned for 45 minutes was when infection control came to inspect the room. Otherwise it was very quick. [redacted]was put in rooms with faeces on the cot handles and black bits of mould around the room.

22. In 2017, [redacted] started getting respiratory problems when she was in 2A and they were trying to force oxygen into her. I can't remember when this was. [redacted] doesn't agree with wires and she always tries to pull her tubes out and the wires too. They ended up bandaging her hands to stop her pulling wires out and that really restricted her with her bottles, she ended up like a kid with no limbs. I had to lift her bottle up for her to drink and they had to tape the oxygen mask onto her face. They then realised that the tape they used to hold the mask on was blistering [redacted]'s face and when they took it off it removed her skin. It got to the point I wouldn't allow them to give her oxygen.

23. On one occasion, [redacted] had surgery to fit her line and the following week she was back in for chemotherapy and they injected her. That night I could see her skin getting really red round about the line so I rushed her back to the hospital the next day. Before I knew it, [redacted] was back in the unit and went down for surgery. Afterwards the surgeon told me that [redacted] had a double port fitted. He explained it was a bit of plastic but that wasn't what I had been shown on the unit. I had been shown a silver metal box with a circle where [redacted] was injected but this double port was different. I don't know if that's what happened and the chemo has burned her skin because it was injected in the wrong place.

24. Eventually [redacted] was fitted with a PICC line which was meant to last two years. This was a catheter that was fitted in [redacted]'s arm. It's a line that's clipped off when she's getting medication and when she's not getting anything, you clip it back on. The amount of times she had been in for medication, clipping it on and off, the hospital managed to snap it themselves so that was another removal because there was no way to get food or chemotherapy into her. [redacted] broke this during her treatment and had to get a port fitted in 2017 or 2018 before the PICC. I was advised that [redacted] was going to have a single port inserted which would be a square silver box. I was shown this silver box and was under the impression this was to be fitted. Instead, a surgeon told me [redacted] had been fitted with a double port made of

plastic. This double port caused [redacted] to have blisters on her skin. I told them that I didn't want the plastic port inside [redacted] again and that I wanted the silver box.

25. There was only a limited amount of staff that could insert the gripper into [redacted]'s chest. It was a type of needle and it moved about a lot. Every time they missed injecting into that hole, they injected my daughter's skin with a long needle. They stabbed her in the skin unwillingly a lot of times and she would freak out, she was telling me they weren't getting the right bit. She was already wound up because there was so many of us trying to pin her down to try and get the gripper needle in and then she would start uncontrollably peeing and pooing again. I couldn't cope with it because that was her telling me she was petrified.

Overall experience in the QEUH (adult hospital)

26. We were in ward 6A once when she had to go in for antibiotics but I asked to get moved out after two days because of the filters on the taps and the air filter in the room. I do not understand why the hospital needed filters if there was nothing wrong with the water.

27. I found staying in 6A extremely distressing and was only able to stay there for 1 night before I had to leave. We were asked to stay in our rooms. I could not cope with everyone having to stay in their rooms. I did not stay in 6A overnight again after this. When I returned to see [redacted] I found that the room temperature was extremely cold.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC

28. I got [redacted] and my Gran to take me back to my house so I could have a shower there because I started to itch after using the showers in ward 2A. I got a verruca from the shower, I never had anything like that in my life. A lot of the kids said that the showers make you itch. I never had a shower in the place again after that. I stopped using the water but I'd been using it to brush my teeth before. I would have a bath and brush my teeth at home. I'd only drink bottles of juice out the machines because I refused to touch the water.

29. I noticed that [redacted]'s bottles were going brown and I told the staff this. I was told that I wasn't washing them properly. I explained that I was and that I had a heated steriliser unit in the room and that I was using the water from the bedroom tap. I only put so much water in each bottle before I washed them in the steriliser. Every time I washed them using the water, the silver bit at the bottom of the bottle looked like it had limescale on it, it always went brown. I put a sponge in one of the bottles and used a knife to swirl it round to clean it. When I brought it out, it had thick black stuff all over it. I knew that the water was contaminated after that but the staff told me it was all in my head. I can't remember the names of the staff, I just recognised their faces at the time.

30. All the wards had the filters on the taps, even in day care. The showers didn't have them but they were awful. Every time I had a shower it flooded. There was one time I had a shower and the water started coming into the bedroom and I had to put towels down because it was coming up the walls and stuff was floating in it. Staff left me there until the next day and then they told me I had to move room. We got moved rooms a lot, the only rooms out of the 27 rooms in ward 2A we weren't in was the teenage bit.

Water issues: communication

31. We were in ward 6A once, in the adults' hospital but I asked to get moved out after two days because of the filters on the taps and an air filter in the room. I complained about the air conditioning but was told nobody else had complained about it until I had come in.

32. I was told there was nothing wrong with the water and that it was in my head all along. I cannot remember the name of the person who told me that the issues were in my head. It was a young member of staff. This happened in 2017 in ward 2A. I was never told anything about the use of water in the ward other than that everything was fine. I was using the water as normal and doing things like brushing my teeth with it as a result.

LINE REMOVALS AND POTENTIAL INFECTIONS

33. In 2017 [redacted] had to get surgery because it looked like she had infections under her armpit at her central line. That left a massive hole under [redacted]'s armpit. I took a photograph of that.

34. At that time, I asked them to remove her central line because it was infected and told them that [redacted] was a 'wire puller' but they refused to take it out and treat the infection. I went home that night and sure enough, [redacted] pulled the line out. You can see the hole and where it's green with the infection, it was like a flesh eating bug and the hole got bigger and bigger.

35. [redacted]'s line was changed twice. One occasion was because [redacted] pulled the line out and the other was because the wire broke in the line and it was hanging down. There was also a point when [redacted] had a double port accidently fitted when it should have been a single port.

36. [redacted] was given treatment all the time for potential infections. I do not know if [redacted] was given new antibiotics for the hole under her arm. I was told that [redacted] was to receive ciprofloxin which is an antifungal medication as part of the hospital protocol on the basis that [redacted] had down syndrome. This was explained that [redacted] would be more prone to getting infections from the ground. No other reason was given.

Infections: Communication

37. The hospital never, ever told me what infections [redacted] had. I looked through some of the data records I got sent but I can't read them all because they get me so upset, I can't go through them. I always knew about Norovirus and Rhinovirus and one of the lab results said she had Astrovirus. There were a few other things but I can't remember what they were. I applied for her medical records from 2017 to 2019 but I'm missing 11 or 12 months of it, there's only a couple of things from 2017, it doesn't really state anything. I know the amount of infections [redacted] had in the first eight or nine months but not once was I told she had an infection. I was just always told it was Norovirus or Rhinovirus. I was told about the rhinovirus by a member of staff because this staff member explained it was the common cold.

PREVENTATIVE MEDICATION

38. [redacted] got Ciprofloxacin. I checked that up, it's an anti-fungal medicine. She got that from the minute she went in there, she was probably on that for about three years. I asked why she was on it and all I got told was, "It's protocol because she's got Downs Syndrome". I told them that it was so she wouldn't catch infections in their dirty hospital. They said that the hospital was clean.

Preventative medication: communication

39. [redacted]had been on so much medication for years and then everything stopped. To me a child should be weaned off certain medications because side effects could happen. The only one she was left on was the Ciprofloxacin, that anti-fungal one. She was left on that for three months after her treatment. I asked why they had left her on this but I was told it was 'Downs Syndrome protocol'. It was supposed to be 6 months but the doctors stopped this after 3 months. [redacted] was still visiting the hospital at this point but her cancer treatment had stopped.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of construction works

40. One day when [redacted] was in getting bloods done, they were doing tests on the fire alarms and that's how I knew the air conditioning never worked right. There was a gigantic vent above a telly and it blew out one day, dust and everything landed on me.

41. The air conditioning and ventilation was not adequate. I found that she was put in a room that was too cold. One of the rooms in ward 2A was so cold, I could see my breath. In general [redacted] has always been at risk from developing colds and flu. I would always keep their home at a temperature of 18 degrees, no matter the time of year to keep things ok for [redacted]. [redacted] developed respiratory problems from the room temperature in the hospital and it made her sicker than she already was. I knew the air conditioning did not work because it was too hot or too cold.

42. The windows and the doors in the bedrooms – you could turn the window and the door and they would come in on you. The internal windows could

open into the corridors. The staff could open the windows from the outside and look in, which meant that if I wanted privacy there was always a risk that the staff would just look in. They once opened the windows to wind me up and it resulted in me losing my temper with the staff.

43. There were a few windows boarded up because that many windows had fallen in on parents. The glass had come in on them.

44. All the rooms we were in were freezing. The only rooms that were warm were the care room, the desk and the two rooms behind it. I had to sleep with my jacket on one night, with three blankets, boots and tracksuit bottoms, on a camp bed that came out the wall. I couldn't even reach it to pull it down.

45. The air conditioning in the hospital did not work in the ward properly and there was poor ventilation. Room 10 in ward 2A was the worst, I could see my own breath in that room. I argued and argued with them, telling them it was too cold.

46. Any time we went to the hospital with [redacted], as an out-patient, we always had to go through A&E. They would try and put you in a room with hundreds of kids coughing and you don't know what they've got. I didn't want them anywhere near [redacted] because her immune system was so bad, no matter what was going about, she would catch it. We would then get taken up to 2A or if there weren't any rooms there, we would get put in ward 4 or ward 3C. They had A, B and C but I can't remember which different bits we were in.

47. In the kitchen there were two seats and that was it, if there was more than two people there everyone else had to stand up. If you were in source you weren't allowed to go into the kitchen and make a cup of tea but the staff were in and out all of the time using it. On one occasion, I can't remember when, the whole of 2A was put in source. There was flu type A, flu type B

and Aussie flu that was going around. Nobody was allowed to use the kitchen, no parents could get to speak to each other and we weren't allowed to use the teenage room. I asked one night if the parents could use the teenage room as it's a massive room but they said no. I asked if I could take in there because there were carpets and a juke box but again, we were told no. I couldn't stand to stay in our room on the ward 24/7 looking at the four walls. You weren't allowed up and down the corridors, you weren't allowed in the kitchen. The only other space you could get was outside and going to the park.

Hospital build issues: physical effects

48. The dust and everything that blew out the vent made [redacted] have diarrhoea and she had to go back in again. I said that whatever blew out the vent that day it made my daughter sick but they said it hadn't. That's when the pigeons were getting into the building so it could have been poo or anything.

49. This happened in ward 2A and it was at some point in 2017/2018.
The room was not cleaned properly. The cleaners could not reach the vents as they were very small and high up. The dust in the vents may have contributed to [redacted] being unwell.

CLEANLINESS

50. I described the hospital as "bogging". It was filthy. The cleaner came into the room and put the mop down the toilet. She then proceeded to use that mop to wipe the floor of the bathroom and the bedroom. I asked her what she was doing. She told me it was a "two-sided mop". I've been a cleaner all my life and I know you don't get a two sided mop. The rooms were supposed to be cleaned for 45 minutes, the cleaners never did that and I asked why not. They said that the room didn't take that long to clean. The only time the room got cleaned for that length of time was when the health people came

in and you knew when they were coming. The room would get pulled apart and we would get shifted about. The next day, after they had gone, it would be back to normal. One day I looked at the cleaner's mops and she had four of what she called 'two sided mops', that was to clean 27 rooms in 2A. If you took a hard surface wipe and ran it over a surface, it came away black. The place was dirty. The place never smelled clean, or of bleach or cleaning products. It just smelled like a dirty mop.

51. [redacted] would never go into a normal bed so they always got her a cot. Every time I got her one, the staff would say it was clean but I took a hard surface wipe and every single bar on the cot was dirty, some had faeces on them. This happened on wards 2A and 6A.

OVERALL EMOTIONAL IMPACT ON [redacted] AND HER FAMILY

Overall emotional impact on [redacted].

52. There was a board on the wall in [redacted] room that has a list of 'What matters to me', it's for you to write up notices so they know how to deal with your child. [redacted] can't physically speak, I wrote on it, '[redacted] doesn't like new faces'. She was only used to me, her dad, her granny and her brothers so I wrote on it that only two people at a time should enter the room as it made her anxious and upset. Time after time it was ignored, they were sending six people in at a time, that's too many faces for her, it just sets her off. She didn't understand. [redacted] got upset, she was uncontrollable. They ended up pinning her to the bed, there was pee and poo everywhere. I had to send them out the room because she was never that scared. This wasn't how [redacted] was, she had never done this.

Overall emotional impact on witness

53. I felt like I wasn't getting listened to, no one listened. The place was killing me, I had anorexia since I was 16 years old. I went from a size 12 to six and a half stone during that period.

54. I knew there were problems with the water but they kept telling me it was fine and it was in my head. They wouldn't listen to me about other things and I got really depressed. I didn't think anybody would listen and it was all in my head. I had lost my dad four months into [redacted]'s treatment. There was a psychologist who came in to the room. I told her that you had to watch the staff like a hawk because they had mucked up with [redacted] and if they had mucked up with her then who else would they muck up with. She just agreed with everything I said, she wouldn't even listen. I ended up looking like a total psychopath, I was constantly arguing with them all. Even at night time when I was trying to chill out, they would sit behind the desk and giggle constantly. I asked them to be quiet but they wouldn't even listen to me.

Overall emotional impact on family members

55. I had to take my son [redacted] out of school for six months. I was told that if he contracted chicken pox and passed this on to [redacted], it could kill her. No one offered us support for him during that time, no schooling. Not even for a couple of hours. He wasn't allowed in the playroom as it was only for patients, not siblings. Eventually they gave him an X-box and a PlayStation, but that was it, that was how he spent his time, every day, all day. He lived there in the hospital with us. He's recently been diagnosed with autism and was showing signs at the time.

COMMUNICATION: GENERAL

56. They observed [redacted] every two hours and I asked if they could send in the same staff and only two members on each shift but they didn't do that. The nurses kept coming in six at a time. That was too many for [redacted] to cope with, too many new faces. I told them that they weren't listening, there was no communication whatsoever.

57. [redacted] couldn't speak but she wasn't deaf. She understood what you were saying to her. I tried to help the nurses with [redacted] because if you didn't do things the way she was used to or understood, she would fight against you as she was scared. I tried to tell the nurses this but they didn't listen. They just carried on and [redacted] got upset.

58. In terms of the move from ward 2A to ward 6A, I found out about that from a friend whose child was an inpatient at the time. I never received official communication about it.

COMPLAINTS

59. I didn't put any of my complaints in writing but I wish I did because nobody would listen. They told me it was all in my head so I questioned why should I write things down. I knew in my heart and in my head that the water was wrong. I can't remember the names of anyone who told me this because my memory is going more and more because of my dystonia, I only remember faces but most of the girls that worked on that unit have all left.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

60. I've never heard of the Oversight Board or heard of Professor White and [redacted] wasn't part of the Case Note Review.

61. I didn't join the closed Facebook group until about seven months ago. It was just Instagram I was on before so I didn't see anything like that. I only followed other families that had kids with Downs Syndrome, that had gone through the same thing as me.

CONCLUDING COMMENTS

62. I told them I wouldn't be back in their hospital and I haven't been back since apart from last Friday, 14 May 2021 because [redacted] had to go back for her teeth. When she was in 2A she had to get 16 of her teeth out after the chemotherapy, which made it even harder for her to eat. They left four teeth in with metal caps over them, which she still has to this day even though all her adult teeth are growing in. I asked them last Friday to remove the caps. They asked me to bring her back in three months time but she's in agony.

63. No child should be in that hospital, or adults. The water - it wasn't fixed for two years and it's still going on. It's still not opening because they can't sort the air conditioning out. At one point, on 6A, they asked the families to make fund raisers for the children to give them funds towards the air conditioning. This was after Kevin Bridges did a whole tour and gave all his money to the cancer unit, so where did that go?

64. There's poo coming into the hospital somewhere. You wouldn't build a super hospital next to a pit containing faeces. These pipes are all linked together and it's right next to the main area where the kids' bloods are tested.

65. The whole hospital is negligent. My daughter went through major heart surgery for a hole in her heart, from when she was born. This was in the old Yorkhill, and not once did she get an infection. As soon as we moved over

here, it was just infection after infection, we knew the hospital had bugs everywhere. It isn't a super hospital, it's super filthy, it is disgusting.

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