



SCOTTISH HOSPITALS INQUIRY

**Hearings Commencing
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Day 13
Thursday 07 October
Morning Session

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10:00

THE CHAIR: Good morning, everyone. I'm particularly glad to see you, courtesy of a negative PCR test. It is however an indication of how we're all interconnected and we should perhaps bear that in mind. However, it's very good to be back here and I'm sorry if people were inconvenienced yesterday.

Now, Ms Arnott, I think we're in a position to hear your first witness.

MS ARNOTT: Yes, my Lord. The first witness is Aneeka Sohrab.

THE CHAIR: Thank you.

Good morning, Ms Sohrab. As you're aware, you're about to be asked questions by Ms Arnott who I think you've had the opportunity of meeting.

A Yes.

THE CHAIR: I don't know how long the evidence will take, an hour and a half, maybe more. I would plan to take a coffee break at about 11.30 so there will be a break in the morning in any event. But if at any stage you wanted to break your evidence before then for whatever reason at all, please feel free to just give me an indication and we'll do that.

Now, I think you're prepared to take the oath.

A Ah-ha.

THE CHAIR: Could I ask you to

raise your right hand and repeat these words after me.

Ms Aneeka Sohrab

(Sworn)

Examined by Ms Arnott

Thank you very much, Ms Sohrab. Ms Arnott.

MS ARNOTT: Thank you, my Lord.

Ms Sohrab, I'm going to begin by asking you a few formal questions. Can I begin by confirming that you are Aneeka Sohrab and that you live with your five children in the west of Scotland?

A (No audible reply)

Q I understand you're here today to give evidence about your daughter who is currently four years old; is that right?

A (No audible reply)

Q In May 2018, when your daughter was 18 months old, she was diagnosed with a type of acute lymphoblastic leukaemia and I believe she was treated at the Royal Hospital for Children and also in the adult part of the hospital before finishing her treatment in November 2020; is that right?

A That's right.

Q You provided a

statement about that experience to the inquiry and I understand you're content for that statement to form part of your evidence to the Scottish Hospitals Inquiry; is that correct?

A That's (inaudible).

Q You've also agreed today to come along and answer some more questions about certain parts of that experience; is that right?

A (No audible reply)

Q Ms Sohrab, could I check that you have a hard copy of your statement in front of you?

A (Inaudible). I apologise.

Q That's okay, we can just wait.

(After a pause) Okay. If you want to look at your statement at any time as you give your evidence, please do. It might help to refresh your memory as we go along, okay?

A (No audible reply)

Now, before we go on to talk about your experience at the hospital, I wonder if you could start by telling us a bit about your daughter before she was diagnosed?

A Before [REDACTED] was diagnosed, she was -- as I've put in the statement, she was healthy, like you would never tell that she had cancer ever. There was no indication of cancer. She was just a really happy

toddler. Just before she was diagnosed, she had just learned to walk so she was like waddling stage. Her eating habits were brilliant. She would eat anything and everything. She was just -- honestly, she would go to everybody. A wee chubby baby. Just an absolute joy, a little girl in little curly bunches. Yeah, she was our princess, our warrior princess now.

Q Thank you, Ms Sohrab. I wonder if you could move your microphone slightly towards you. It's quite faint.

A Is that better?

Q Hopefully. We can try again if we need to.

Okay, we'll get started if that's okay. Ms Sohrab, I'd like to begin by asking you about the events around your daughter's diagnosis up to the point that she was admitted to Ward 2A in the Royal Hospital for Children. Could you begin by describing the circumstances of your daughter's diagnosis?

A It was -- I'd noticed a small bump form on the back of her head, so it was on the left-hand side, just at the lymph node, right at the back of her head. It would grow and then it would subside and I wasn't really too sure on it until my sister-in-law had said, "That's nothing to worry

about", because her daughter had had something similar and it's very common in young children. Took her once to a GP who said, "It's not bothering her and it's fine, she's a small child, her skull is growing, it will grow into it". So it was fine, didn't think anything of it until it became quite substantial and it looked to me like an infection. Do you know like a pus-y infection? It became quite big, like a big ball of pus at the back of her head.

And then my sister-in-law came round again, it was several months later and she said, "Have you not checked that out?" and I said, "Well, you asked me not to; you told me it's fine, you know". She said, "No, go and check that out". The day I did, the GP didn't say anything but he referred her to the hospital. He said, "We'll get it checked out, it might just be fluid or whatever it is, but we'll get it checked out".

So I got an appointment with the hospital surgeon and that was about two to three weeks from the hospital -- the GP referral. Once the appointment came in, initially the surgeon again reiterated the fact that, you know, small children are growing and you have common -- very common to have lumps and bumps in their head until he actually moved her hair and looked at

it. Then he started saying to himself, "Right, we need a biopsy". At that point I didn't understand these terms, the medical terms, "We need a biopsy, we need a da-da-da", and I was obviously quite astounded and quite physical, like, "What do you mean, in terms of what?" and he said, "No, no, nothing to worry about, might just be a retention of fluid, it might be anything but we need to get it, you know, looked at. We need to take her in for tests". I said, "That's fine".

Assuming, you know, that what he's saying, it's a trapped nerve or the retention of fluid, as the usual hospital appointments come, it's months/a year long on the NHS waiting list, I'd assumed that, but within the next few days I got a call from the same surgeon saying there's been a cancellation and take up the date of the cancellation. And I think I was at college when I had a test and I explained that and he said, "Well, if you don't take it up then, there will be a six-month wait for an appointment". So I took up the appointment and [REDACTED] went in for a biopsy that day.

On the biopsy, everybody was being really nice. They really kind of understand. And I even took her -- now I recall -- took her to the pharmacy as well, when I got nervous,

my sister-in-law reiterated, "Go and get it checked", so I wanted to find out, when you get that panic, that, oh my -- you know, what's my child -- what is happening to my child and what is this? You use everything, you use Google, you try all -- I went to NHS 24, I went to the pharmacy, I went to the GP trying to figure out what it is, because you want answers and you want them fast as a mother.

But the pharmacist woman, she said it was a mass and then I'm trying to Google what "mass" is, so I had a sort of pre-indication that it might be cancer. And when we went in for the biopsy a few days later, another surgeon called me and said, "Can you bring her for blood tests? We need to take some bloods just to confirm, you know, what's happening with [REDACTED]". I said, "Of course". Again that day I had an exam, took her up after my exam and it was when I met Dr Shazia Chaudhury and she explained that [REDACTED] had cancer and she was admitted from that day. That was the 11th --

Q 11 May 2018.

A '18.

Q Just pausing there, Ms Sohrab, how did you feel when you received that diagnosis?

A Destroyed our world. This is my child, my baby. I remember

saying to her, "She can't have cancer, she can't have cancer. It will be me. I've got cancer, it'll be me that'll have cancer, not her. How could she have cancer?" It was disbelief, extreme disbelief, shock. Just obviously, it just completely destroyed our world to get that -- crumbled.

Q Okay, thank you.

What I would like to do now is look at an overview of your daughter's treatment for leukaemia and then I'm going to move on and explore certain parts of your experience and your daughter's experience in more detail.

I think initially your daughter was admitted as an inpatient to Ward 2A; is that right?

A That's right.

Q And her initial admission was, I think, for around about eight weeks; is that right?

A Yes, that's right.

Q What kind of treatment was she placed on in that initial period?

A In the initial period it was quite an intense form of treatment. It was very -- it was initial stage. Again, my memory doesn't serve me right but it was the very initial -- where she was given a heavy dose of steroids. She was given a lot of medication to start off with which made her lose her --

obviously lose her hair and gain a lot of weight because of the daily steroids. Then she got the problems associated with taking as many steroids as she was. She wasn't sleeping all night. She wasn't -- the effects of the treatment that she was receiving, I don't remember the names of all of the medication, I'm going to be honest, is I left it in their hands because whatever they would give saying it'd make her better, they are the experts, I would give it to her. The medication was given to me, "Can you put this down her NG? Can you put that down her NG?"

Q I think you say in your statement that your daughter was placed on a high-dose chemotherapy trial; is that right?

A Yes.

Q So it was very intense treatment?

A Yeah, ALL trial, 2011, and I was told she was lucky to be on it. It was near the end of the trial.

Q I think for the remainder of your daughter's treatment she was both an inpatient and an outpatient --

A That's right.

Q -- in the children's hospital and the adults' hospital. Then the treatment finished in November 2020 and, as I understand, your

daughter has moved on to regular check-ups now; is that right?

A That's correct.

Q Ms Sohrab, just before we move on, were you with your daughter for most of her treatment during her admissions?

A I was there mostly, but overnight stays, I mean, I stayed with her when I could stay with her, but because I'm a single parent, I've got four other children who require taking care of. So overnight it was my parents, my mum, my dad helped out. Again I had issues with -- I mean, at times, barely [REDACTED] had to stay -- I would come and go and come and go as much as possible, drop the children off. Or when I was staying with her, I would, you know, get up, drop the children off to school, come back, go and pick them up, drop them off where necessary. Yeah, very --

For herself, different people sitting in with her, auxiliaries, nurses at times, left on her own when there's not enough staff, because we couldn't take her obviously (inaudible). During the eight weeks initially, yes, I was there constantly with her but then I found out the effects on my other children, because they are children as well and they need their mother as well. It's a tough balance.

Q Thank you, Ms Sohrab. That's very helpful.

What I'd like to do is move on now to think about those first few weeks on Ward 2A of the children's hospital and your experience there. Now, you've touched on this but could you describe what sort of information you were provided with about your daughter's treatment at the beginning?

A What sort of information? I was given a big pack, I remember that. It had a lot of medical terminology. I had a meeting with Dr Shazia Chaudhury who explained in kind of, you know, normal human terms what is happening to ■■■■, what kind of treatment she'll be getting going forth. Shazia is lovely, she's very approachable. All the doctors and nurses are very -- they're very good at what they do, but there is this pressure, same pressure on top of them, which I feel --

Q Okay. I'm sure we'll come on to that later in your evidence.

A But initially the information that I received was the treatment that ■■■■ would get, the big pack, there was a lot of leaflets. There was a lot of reading required and I feel that, personally -- I don't know how other parents feel -- I wasn't in the correct mindset to be sitting down and

actually reading these things. You were told not to read up on them when you're trying to Google things as well because hands up that -- MLL rearrangement, after reading a lot of things, now I know what MLL rearrangement is. ■■■■ is now a year into remission. MLL rearrangement, what I was told is that it is a malformation of the DNA cells, of one of her genetic DNA cells. It's a genetic malformation.

But when I'm trying to find out, when you're Googling things and then you're asking questions: what type of MLL rearrangement is it; will the chemotherapy work in terms of will it burn off the rearrangement because you're on to regiment C, which is the highest dose of chemo, because she's high risk for a relapse because of the MLL, and I've seen children relapse with MLL. So it's -- you know, as a parent, it's like you want more information and I was pressing for information but I felt I was being pesty, because I wanted information and then, when you don't get information --

Q We'll come on to communication at the hospital further on in your evidence but, just to clarify, and this is in your statement, but when you say "MLL rearrangement", that was the particular type of leukaemia

that your daughter was diagnosed with; is that correct?

A No, she had -- that was part of it. She had ALL, which is acute lymphoblastic leukaemia, type B, and she also had MLL rearrangement -- with MLL rearrangement.

Q Okay. So I think you've confirmed that, at the beginning of your daughter's treatment, you were provided with a lot of information and you had a discussion with the consultant as well, but I think you're describing to us that you felt somewhat overwhelmed by the amount of information you received at the outset?

A Yes.

Q Ms Sohrab, what, if anything, were you told about your daughter's vulnerability to infection at this early stage?

A The words were used that, "If anything happens to your child, that it will probably be due to infection rather than the cancer itself". Because I was geared -- I was very emotionally -- as you can imagine, a parent that's just found out her child has got cancer, my hair was falling out before her hair was. I was very stressed, depressed, emotional. Hence the information given at that time I felt was very overwhelming, too much was given and in medical terminology which I

didn't really understand. And at that point -- So, your question was?

Q No, that's quite all right. I think you've just indicated that you were aware from the start that the risk of infection was a significant risk to your daughter during her treatment?

A Yes, absolutely.

Q We'll come back to this later on but can I just ask, at this stage was your daughter fitted -- did she have a procedure to have a Hickman line fitted at a certain stage?

A Yes.

Q Could you just describe or just outline what that procedure involved?

A Hickman line? Hickman line, they give the child general anaesthesia and after general anaesthesia they operate on the chest and fit in the Hickman line.

Q So it was a surgical procedure --

A Surgical procedure.

Q -- under general anaesthetic, yes?

A Under a general anaesthetic, yes, because she's so small. She also had a nasal gastric tube for the duration of her treatment. I was one of the children that I was told was particularly sensitive to treatment. Her hair even fell out after treatment

and her eating habits were next to nothing. She was on water boluses; she was on milk feeds for the -- mostly part of her treatment. She was very sensitive to it I was told, so --

Q Was the procedure to fit the nasal gastric tube also a surgical procedure?

A No. The nurses do that and I had to pin my daughter down every time. And you can imagine how traumatic it is for her and for the parent. Obviously, it's a nurse's job doing it day in day out. When you're holding your own screaming child down, it is very emotional and you have to close your eyes and try to drown out the screams. And, obviously, that child is wondering "why my mother is pinning me down" while they're inserting a tube down her throat, that sometimes comes out of her throat and sometimes it goes down, and then sometimes the nurses poke the wrong bit in the nose, causing trauma. It's not easy. It took three women to pin her down because obviously she was very traumatic -- traumatised.

Q I'm going to start now by asking you some questions about Ward 2A. We will come back to your daughter's treatment further on, but I'm going to ask you now about the ward

itself and the facilities on the ward, okay?

A Sure.

Q So thinking about Ward 2A, when you were first admitted, could you describe what facilities were on the ward available for children?

A On Schiehallion Ward? Schiehallion Ward, it had a lovely playroom for the children. It was very - - more than adequate, the equipment, lots of toys. It had a play-leader that was mainly based in the playroom. It had a kitchen facility, a fridge, dishwasher and the usual kettle, tea/coffee facilities were available to parents. That was in the kind of like kitchen/parents' room, and the playroom, which two rooms were vital for children and parents most definitely.

During the first eight weeks, before [REDACTED] was put into source I remember for a month near the end of that, so I think I was just using those facilities for the first month. Those facilities obviously in the room, you have your -- the main room where the child and the parent sleep, the parent bed and the child bed and the shower room. That's the facilities in Schiehallion.

Q I wonder if we can just come back to explore some of that a

little bit more. How would you describe the environment of the playroom? Was it something your daughter used?

A Absolutely. It was a lifeline for the children because they can't go out the ward. That is really all they have, apart from if you were in a room where the TV was actually working. Other than that you could request to use a tablet if you didn't have one of your own, because these children are tied to beds for hours at a time or else on drip stands. They had to have them -- during the initial treatment, they're on liquid -- water constantly. The drip stands went with them everywhere. And if you didn't have any sort of amusements for young children, as you can imagine, it's impossible to keep them, you know -- either they'll pull the Hickman line, you have to be very careful, or the NG tube, so it's constant.

Q I think in your statement you also describe the playroom as a "chilled and safe space"?

A Absolutely, yes.

Q What made you feel it was a safe space for your daughter?

A It was a space to go in and play. When her siblings came, at times they would be allowed to go in and play with her as well. She was

allowed to be her little self, you know? Whereas -- yeah, she enjoyed it.

Q You've also described the kitchen that was on the ward. I think you've described that that was a vital facility. Can you tell us why you felt it was so vital?

A Because that's where parents met other parents. You could speak to other parents with the same -- who were in the same boat as you, and very similar circumstances. You might have different types of cancer but cancer is still cancer, and they tell you their experiences. I mean, it was in the playroom -- sorry, in the kitchen, I was sat crying one day and another father basically said to me that, "You need to stop crying and help your daughter get better".

Q Okay, so you found support from other parents in the parents' kitchen?

A Definitely.

Q You indicate in your statement -- and for those following, we're looking at around about paragraph 22 -- you indicate in your statement that the kitchen was closed for some of the time that you were there. Could you tell us about that?

A That happened I think -- 22, sorry, I'm just getting to it. Yes, okay. So the kitchen had closed and

that was I think when I got into source. and I were put into source the second month because of a serious infection. Again, to date, I don't -- I only found out about some infections, what they were and how serious they actually were on the child case note review. So, yeah, the kitchen was closed.

Q Did the parent kitchen itself close to all parents on the ward?

A To all parents, yes.

Q Were you told why it was closed?

A There was things happening around that time. The taps were getting fitted with filters. I remember before it had closed, the taps in the kitchen were sealed off. You weren't allowed to -- there was bottled water to use in the kettle but you weren't allowed to use the taps in the kitchen. There was notices up, "Do not use for drinking water, do not use", in the kitchen and in the rooms, the men came to put in the filters.

Q We will come on, Ms Sohrab, to talk about the water issues that you describe in your statement, but am I to understand from what you've said that the kitchen was effectively out of use because there was no water in it; is that right?

A I think so, yeah.

Q Okay, and how did you

feel about the kitchen closing?

A We needed it, in terms of the parents, to heat our food up because if you're getting takeaways or, you know, you've got food that someone has brought in for you, you need facilities to heat that food or else you're left with cold sandwiches and things.

It was vital for support. It was a very necessary facility. It wasn't, you know, just have it as an extra. It's a vital facility for people that are staying and they need somewhere -- they need a microwave to heat their food up, they need to make cups of tea and they need to speak to other people if you're living in a place like that.

Q Thank you, Ms Sohrab. In your statement you also describe the level of care and culture on Ward 2A and I wonder if you could explain what you mean by that? This is around about paragraph 23 of your statement. I should say, we'll come on to think about the other wards you were on. I'm interested to understand your experience on Ward 2A at the moment.

A Sure. I mean, what I would like to say is Schiehallion nurses -- you can't get another Schiehallion nurse because the Schiehallion nurses are very experienced in what they do.

The doctors, the nurses are amazing at what they do. But the culture in terms of dealing with people, it was quite -- the nurses' stations, if -- some can be nicer than others; some can have different types of attitudes. You're dependent upon which nurse that you're dealing with and who you're dealing with, who's holding your child down.

Again, as I said to you, you know, I had to quickly get over my own emotional feelings and start to -- because, initially, I never used to hold [redacted] down, I would have to step out. It was too traumatic for me to pin my own child down. But then I started to see things and kind of became involved more with [redacted]'s care.

Yeah, nurses, the nursing staff [reads to self]. Yes, again, what I've said is absolutely true, that they don't have the experience, in 3A, of the nurses in the Schiehallion nurse [sic], but there is definitely a culture in the Schiehallion nurses that was very -- felt like a -- kind of like a schoolgirl environment.

Q I think you're indicating though that, in terms of the treatment and the care they were providing, they were the experts in doing this?

A Absolutely.

Q So you felt they had

specific expertise that your daughter needed for her treatment; is that right?

A Yes. Their expertise is spot-on, but when dealing with people, it's --

Q Now, you also say, and this is around about paragraph 26 of your statement, that the Infection Control Team were often on Ward 2A

I'd like to ask you a few questions about that. Did you observe the Infection Control Team on Ward 2A yourself?

A They had meetings with us, the parents.

Q Is this early on in your experience of Ward 2A?

A Yes, very early on, yes. They gathered parents and they had specific meetings with us before the kitchens and the facilities were closed. They tried to explain to us kind of what's happening. Again, it was all very airy and I didn't really understand it that much at that point in time, but something was going on is the way that it was interpreted. Infection Control. Nurses would be, "It's all Infection Control that's doing it, it's Infection Control that's doing it". There was extra cleaning put in, extra kind of measures were put in, cleanliness measures were put in, filters were put in, but we were told, "It's all infection

control, it's all them". It's a lot of blaming going on: they do that, they do this.

Q I'll come on to that in just a moment, Ms Sohrab, but I'm interested to understand what your recollection is of these meetings that the parents had with Infection Control; can you recall what was discussed?

A There was certain -- I think they took in all parents at that point in time, but there was a few in each meeting. What was discussed? I remember the cleanliness, if we had any issues with the cleanliness, the routines of cleaning, how many times things are cleaned. In source what happens, how many times things are cleaned in source. They just really wanted to keep on top of things, we were told at that time. Why? Is it tied in with the water situation? Is it tied in with the ventilation situation? Obviously the Schiehallion Ward is a building site now, but I don't know.

Q Sorry, are you indicating that they didn't explain to you why there were these rules and protocols?

A Yes.

Q But they were telling you, "There are these certain rules and this is why we're here"?

A Yes.

Q But just not why at that

stage?

A Yes, and the questions they were asking us was in relation to the cleaning side of things.

Q Okay. So they were asking you questions, was this about what you were doing or about what the staff was doing?

A What the staff was doing, what the cleaners were doing, and they would come and inspect the cleaning. Infection Control consistently inspected the cleaning in the ward.

Q So am I right in thinking, just thinking about the timescale that we're looking at, that this is over the summer of 2018; is that right?

A Yes.

Q I think you've already alluded to this but you describe the staff on Ward 2A as having a particular attitude towards the Infection Prevention & Control Team. Could you describe what that was?

A When you had some sort of a kind of issue, "But it's Infection Control, it's Infection Control, it's them, it's because of them we can't do this". Or if the playroom got closed, "It's Infection Control". What happened? Obviously, everybody must have asked the same question as I was asking because, as I explained, it's a

vital facility not just for my daughter but for all the children in the ward. "It's Infection Control, it's Infection Control". Everything was put down to Infection Control, and Infection Control would come in and they seemed like the Big Brother on top.

Q I think you say in your statement at paragraph 26 that the culture of the staff on Ward 2A got to the point where they viewed the Infection Control Team as "pesty", I think is your word?

A Yes.

Q Was your impression that they felt the Infection Control Team was getting in the way and interfering?

A Interfering and rooms were closed if the cleanliness wasn't good enough. Infection Control came up and, you know, just -- in different rooms at different times without warning, just to look at the cleanliness in the room, and they would monitor everything, write it down and go back and feed back. There was a lot of pressure put on to the cleaners I felt because they were constantly rushed off their feet and because they had so much to do. The little cleaners were always kind of in and out, rushed and away.

Q Ms Sohrab, were you reassured by the fact that Infection

Prevention & Control were on the ward quite a lot?

A Was I reassured? Sorry, was I reassured?

Q Were you reassured by the fact that Infection Prevention & Control were there inspecting and monitoring or did you feel differently about that?

A I felt a bit differently about it because you don't understand why they're there. Their name is Infection Control but all they seemed to be doing was looking at the cleanliness of the rooms. Again, I didn't really understand why. In source, I remember when you're in source the room is cleaned more than a child who is not in source. So that's all I really felt their role was. I didn't --

Q So did the presence of the Infection Control Team in fact make you feel as though there might be a problem on the ward?

A Yes.

Q In your statement you also describe I think a knock-on effect to the parents from the staff's attitude toward the Infection Control Team. This is again at paragraph 26, it's towards the end of that paragraph. I wonder if you could tell us about that.

A Okay. I was actually told, I remember, by Dr Shazia herself

that you can't put teas and coffees or anything down the drains because that's what's causing the problems in the ventilation and having the issues on the ward. So we were told not to -- you know, the other teams have told her, yeah, other teams (inaudible), and that's why Infection Control were down so often.

So we came to a point where if you've got a cold cup of coffee or water or liquid, normally if you pour it down a sink, you know, it's no danger of spillage or burns or anything like that. You're having to leave everything just on the trays on top of the bins in the hope that it won't spill because you couldn't put it down, or you couldn't wash any dish. Because if you're in source, you can't leave the ward and you don't have any kitchen facilities anymore and you're left with unwashed dishes, and nobody is going to wash them for you. The only facility you have is a sink to do it but you can't use the sink to do it because you're told it's causing issues.

Q I think you indicate in your statement at that paragraph and elsewhere that you felt the staff were blaming the parents for some of the problems on the ward; is that right?

A Again, that's it, that's the whole pouring --

Q How did that make you feel?

A Obviously not good because we don't have any other facilities. What else can we do, you know? You are -- you're in, we do need to eat, we do need to drink. How much can we be expected from two floors or six floors to go out three/four times a day to eat and drink? They had people brought up food. I'd like to obviously -- if my daughter's not ate something -- dispose of the food, wash the plate and put it back. But if it's -- we were then told, "Just leave it, leave it all", and your own dishes are --

Q Okay, thank you, Ms Sohrab.

I'd like to move on now to ask you about any observations you have about water on the ward and you've indicated already that you had some of those. So in your statement, I think you indicate that you remember there being issues with the water right from the start --

A Yes.

Q -- of your admission; is that correct?

A Yes.

Q This is from May 2018?

A Yes.

Q Would you describe what you saw? For those following the

references in the statement, it's paragraphs 36 and 37.

A Okay, yes. The taps were sealed, there were signs everywhere. So again not understanding what's happening, why taps have been sealed. No explanation was given. The usage of bottled water, the usage of bottled water, taps were sealed and filters going on.

Q I wonder if we could explore some of that in a bit more detail.

A Sure.

Q Could you explain what you mean by taps being sealed?

A They were wrapped in the kitchen. I don't know what with, I think it was cling film or something. Completely wrapped up --

Q So that you could not possibly use them?

A No.

Q Okay. And what did the signs that you saw up say? Can you remember?

A "Do not use". "Do not use", I think or something. It was "Do not use water" and there were big signs, handwritten signs.

Q Do not use the water for any particular purpose or at all?

A No, it was just "Do not

use the water" or "Do not open tap".

Something along the line --

Q Was that in the kitchen or was that in the bedrooms?

A No, no. Kitchen. In the bedrooms you were allowed to when the filter was on.

Q Okay. Yes, you've described filters on the taps, so once the filters were placed on the taps, you could use the water for anything?

A You weren't told particularly what to use it for but I wouldn't use the water for drinking water.

Q Were you able to drink the water from the tap if the tap had a filter?

A I wasn't -- I didn't ask that question but, personally, I wouldn't, you know, drink water that everybody used as a hand-wash basin. We got bottled water for a long period of time and there was a point in time that they came back with jugs. Jugs of water were given, because initially that's what used to happen: every room would have jugs with ice in it and everyone would be given one. Then that stopped and everybody was given bottled water. Then that stopped and jugs came back. I remember being in with [REDACTED] at one point and my dad was staying overnight and my dad went to

drink the water, and my brother said "Drink the water? Is that safe?" He asked and (inaudible) it's safe.

Q So, are you indicating, Ms Sohrab, that there was a period where you could use the water to drink but then you were given bottled water to drink for a time?

A Yes.

Q But then there came a time where you were again allowed to drink the water?

A Yes.

Q And in fact you've indicated that your family were given jugs of tap water you think?

A Tap water, yes.

Q How did it make you feel to see these issues with water on the ward?

A I think the biggest impact hit me when my daughter was given medication to stop infection due to water issues, is what I was told. I was not told that there would be long-term damage to her because of taking this medication, high-dose antibiotics for something that's related to a hospital. It makes me very angry. It makes me - that's not fair on a small child to be given that. Not enough information was communicated, and if things were, they certainly weren't communicated in terms of what was happening, why it

was happening, why is water safe one day and not safe one day.

Q Ms Sohrab, I can reassure you we will come back to talk about the preventative medications that your daughter was given.

A Sure.

Q But just thinking again specifically about the water issues, did it make you feel safe to be on a ward with these taps being sealed up and filters on the taps?

A No, absolutely not.

Q Just to cover that ground again, I think you're saying there was no communication with you about why this was happening?

A If there was, it must have been very limited but I can't recall any. I'm trying to test my mind. I can't recall any. "Infection Control, Infection Control", is what I remember. "Infection Control, it was Infection Control. Ventilation issues". I remember Shazia explained the ventilation issues. There was water issues because parents were putting things down the drains, washing their dishes and cups of tea and coffee down the drain. So that's what I understood it to be. Nothing more.

Q Ms Sohrab, you do reference in your statement a discussion with Dr Chaudhury and I

will come on to that later, but are you indicating there was a discussion around the summer of 2018 with Dr Chaudhury where she mentioned to you water issues and ventilation issues?

A Yes.

Q What did she say to you about ventilation issues on the ward?

A It was due to -- there were smells coming constantly, really sickening smells to the fact that you're actually walking and you're actually going to vomit, it's that bad, from the sewage site next door. You're in the playroom, you can smell it and it smells like -- you can imagine it doesn't smell very nice.

Q So that was a smell that you could smell in the ward itself?

A In the ward, in the playroom, yeah. You had to actually cover your mouth. It was sickening.

Q What was the effect on your daughter of that smell?

A I can imagine -- I actually don't want to imagine the effect on my daughter. It was, for me being an adult, you know -- times in the car park when you're -- and it's the strongest at certain points, you feel sick to the core. Like actually your stomach is going to come out. The kids had to cover their mouths, run inside, and you're inside

you can still smell it.

Q Okay, thank you.

Were you ever told not to wash your daughter with the water in the ward?

A (No audible reply)

Q Were you ever told it was safe to wash your daughter with the water in the ward?

A It was never (inaudible) to wash my daughter in the water or not.

Q Okay. You also mention in your statement, and this is around about paragraph 41, that there were some issues with the showers on Ward 2A, could you tell us about those?

A Showers, when they were -- they're supposed to be draining when, obviously, you're having a shower. There's not a tray, a shower tray where the water will drain down; it's just like open space. Well, you expect -- the expectation is the water will drain into the drain. It drains into the room. So once you've had a shower, if you're going to walk out to your room, you're walking out with a puddle into your room or for the rest of whatever -- however long it takes for someone, a cleaner, to come and clean it up for you, and how many towels you're going to use there. If

you're sat on the toilet, for the duration of the day until a cleaner comes, you know, you're basically walking into a big puddle.

Q So a puddle was left in the room sitting there until someone would come and clean it up?

A Yes. It could be into your actual bedroom or it could be into the bathroom area.

Q Did you have concerns about the safety of that situation?

A You could fall, you could hurt yourself when you're taking your child in and out to bathe them. It's just not very appropriate.

Q We're going to come on to talk about the fact that you moved rooms quite a lot in the ward, but just while we're talking about the showers, I think you indicate in your statement that this flooding didn't happen with every single room that you were in?

A No.

Q So the showers in some rooms were okay as far as you recall?

A Yes.

Q But not others?

A Some were okay. Some it was big puddles. Some the puddles went out of the room. Some puddled up beside the toilet. It really depended what room you were in.

Q Okay, but it was

something you experienced in more than one room; is that right?

A Yes.

Q Now, in your statement you say another feature of your experience on Ward 2A was the fact that you were moved rooms quite a lot. Could you explain what your recollection is about that?

A Sometimes without warning, "You're moving to room X, Y, Z". Don't know why. There was no reason given. "The child is going to this room"; "Okay", and your stuff was pack and you're taken. That was it really. And again it became a force of habit, didn't question it, just went along with what was happening.

Q How often do you think this happened?

A Very often. Yeah, very often. You're in one room -- sometimes -- I mean, I assume maybe because of how sick a child is, they've been placed closer to the nurses' station. I don't know. That's my assumption. I'm hoping that's the situation but again you're not told.

There were rooms that had been completely whitened out with sheets and things as well when you're told the ward is full. There was rooms available, I don't know why they were sheeted out. Yeah, lots of times.

Q So are you indicating that sometimes you saw rooms that were closed off with white sheets? Is that what you --

A White sheets.

Q Did you form your own impression of why you were being moved rooms?

A I'm assuming -- my impression is when a child is moved closer to the nurses' station, is that because they're sicker? The other times, no idea. Because it's not just once or twice it would happen, it would happen a lot of times.

Q I think in your statement you indicate it was literally hundreds of times; is that right?

A Yes. I mean, you don't have any -- it becomes habitual. You know, you get used to it. You can get up and, "Right, your child is going to this room today", someone walks in, "Okay". You just agree and go with the flow.

Q I think you also describe in your statement that sometimes you would leave the ward for a short time and come back and find your daughter had been moved?

A Yes.

Q She wasn't in the room where you'd left her; is that right?

A Yes. Lots of times and

then I'd have to find out where she is.

Q What was the effect of these frequent room moves on you and your daughter?

A For a child, psychologically, even till today -- she went to hospital, when? -- yesterday -- we went to hospital a couple of days ago and when she sees the colour blue, psychologically, it was -- the girl was traumatised. She stopped speaking, she regressed in her behaviour. She stopped speaking, she got down to grunts, just "ugh" for communication. And she stopped walking, stopped talking, she just became like a vegetable and just let things happen.

Obviously, she fought back when she thought people were going to hurt her, like when the nurses came in, two or three of them at a time, and they would pin her down to give her bags or cannulas, which is extremely traumatic when they can't find a vein. They have to go in the feet and elbows and various parts of the body to try and get a vein for her. Extreme trauma for my daughter, for a person. Myself, I was scared of needles before and I've had to experience that with my daughter every single day basically.

Q Thank you. We will come on to reflect on your overall

experience towards the end of your evidence but for now I wonder if we could stick with your experience on Ward 2A and what was happening. What I would like to move on to now is to talk about -- you describe in your statement that your daughter was placed on different wards sometimes, that she wasn't always on Ward 2A

So I will come on to ask you to describe your experience on these other wards but I've just got a few questions before that. When you were sent to another ward, were you told why you were being sent to another ward?

A Because the Schiehallion was full.

Q Okay. You were told that Ward 2A was full and there was no space. How often did that happen?

A (No audible reply)

Q And did you form your own impression of why it was happening?

A Just because of infections, the increase of infections in children. That was my own opinion of why it happened, but when you're actually walking through the ward and the rooms were sheeted out, it was a question mark as I thought the ward was full.

Q When you say the rooms

were "sheeted out", is this what you described a moment ago about rooms being closed with white sheets being put on them?

A Yeah.

Q So was your perception that this closure of rooms affected the capacity of the ward?

A That's what I think, because if every room was actually used for a child, would the ward be full?

Q Ms Sohrab, I would like to think now about your experience on some of these other wards within the children's hospital. I wonder if you could tell us firstly how the facilities on these other wards compared to the facilities on Ward 2A?

A It was -- in particular 3A was used as a kind of ward for the children. The facilities were good. They had a playroom there as well; the nurses were lovely there as well. Weren't so judgmental but not as experienced as Schiehallion nurses. I'd definitely give them that.

Q Okay, and was there a parents' kitchen on Ward 3?

A Yes, there was.

Q How did you feel about the facilities on that ward?

A Well, if they'd been taken away from 2A, when you get them on

3A, then you prefer being on a ward that you have them.

Q Thinking about what you've already said in relation to water issues on Ward 2A, do you recall whether there were any water issues on Ward 3A?

A If a child from Schiehallion is going into 3A, that room had to be fitted with the filters.

Q The filters on the tap?

A Yes. That was -- I mean, at times we had to actually wait for the man to come in and to fit the filters and then we were moved. Because we'd be waiting in day care, "Oh, the man's here to fit the filters", and once he'd fitted the filters onto the taps, then you could go into the room.

Q And were there any issues with the showers on that other ward?

A The showers were just generally the same. It's not 2A, it's throughout the --

Q Okay. Moving on to think about some other aspects of your experience on Ward 3, you indicate in your statement that the care and culture on those wards was slightly different from Ward 2A. Would you like to describe that to us?

A I think the nurses -- I just felt their attitudes were a little nicer.

Their expertise wasn't -- I don't know, maybe they've not got that pressure that Ward 2A nurses have, but they were friendlier, more approachable.

Q Now, when you were on these other wards, so outwith 2A, was your daughter still seen by Ward 2A nurses or doctors?

A It was very difficult to get hold of the nurses and doctors when a child is on 3A. They're supposed to be coming down after the ward round is done at 2A and then the child is seen in 3A. That is the routine. Again it depended upon how busy 2A was and emergencies and if someone could come down.

Q So you're describing that on the other wards it could sometimes be more difficult for the Schiehallion staff to see your daughter; is that right?

A Yes.

Q Okay. I'd like to move on now to think about the time when Ward 2A closed. Can you tell us what you remember about finding out that Ward 2A was closing? For those following the statement, we're around about paragraph 29 here.

A What I remember about the ward closing?

Q What were you told about Ward 2A closing before it

closed?

A I had a meeting with Dr Shazia Chaudhury and we were told, due to the water issues and due to ventilation, that Ward 2A Schiehallion will be closed, but we're going to get moved into Ward 6A. And I questioned her at the time, "Is the water not the same throughout the hospital?" She couldn't -- she didn't reply.

Q I'd just like to think about that in some more detail. Do you recall when this meeting was, even approximately?

A It was after summer, I'm sure.

Q Is this the same meeting that you referenced a short while ago with Dr Chaudhury?

A In terms of it was the meetings when you're told -- in terms of what, sorry?

Q I think you mentioned earlier on in your evidence that there was meetings where the issues with infection control were discussed and you had a specific meeting with Dr Chaudhury where that was discussed?

A No, because we had various meetings with Infection Control, they were separate to this particular meeting and it wasn't in relation to Infection Control and

Infection Control were not -- she didn't blame Infection Control. She said it's due to the issues, water issues and ventilation issues.

Q So, as far as you recall, there was one meeting with Dr Chaudhury where these issues were discussed?

A Yes.

Q Okay. Can you recall what she said about the water issues?

A She said there's issues with the water. I won't say word for word but what I recall is there was issues with the water and the ventilation system.

Q Okay.

A And that's why the ward is having to be closed down and we've got another ward in the hospital, in the adult hospital, which is Ward 6A. And I was very -- "Isn't the water the same throughout the hospital?"

Q So you're indicating that you asked Dr Chaudhury why because the water is presumably the same in both?

A Yes.

Q And what did she say to that?

A Nothing. She didn't have an answer.

Q Didn't have an answer to that.

A Yeah.

Q Can you recall what she said about the ventilation issues?

A There was issues with ventilation but they weren't really specified. I assumed it to be the smells coming, the strong smells of whatever sewage it was that you breathe in from the car park. If anyone has ever experienced it at peak times, it's sickening to the stomach. I assumed it to be that to possibly increase the ventilation. It was an assumption.

Q Okay. Did this meeting take place just shortly before the ward actually closed or was it sometime before it?

A It was very shortly. I think the closures were in the next few days but it was literally a two-minute (inaudible).

Q Okay. I think you've already indicated that you had a concern about whether moving to Ward 6A would in fact resolve the problems with the water?

A Yes.

Q As far as you were concerned at least?

A Yes, because you questioned, well, is the water not -- the question I had: the water is the same, so --

Q You indicate in your statement at paragraph 29 that you felt sorry for Dr Chaudhury at that meeting. Could you tell us why?

A Because I felt like she's very, very, very good at what she does, amazing, very approachable, but, again, passing the information down to parents and not having the answers for parents, I feel sorry for her.

Q So you felt that she was unhappy that she didn't have the answers for you?

A She couldn't give me the answers. Being put in a position -- she was put in an awkward position.

Q I'd like to think now, Ms Sohrab, about the arrangements for moving children to Ward 6A. You talk about this in paragraph 30 of your statement. Just to clarify, were you and your daughter in the hospital on the day of the move to Ward 6A? I think this was around about 26 September 2018.

A I don't think we were. I don't recall it, no.

Q Okay. You mention at paragraph 30 that you had some concerns about the lack of information about the arrangements for moving to Ward 6A; is that right?

A Yes, ah-ha. There was a

lot of -- it was a big move for the staff, for the children, a lot of getting used to. New arrangements, new layout of the place, new rooms. There was a lot of getting used to. So notes and things -- when you had issues, it was "We've just had a move, we're just getting used to situations, we've had a lot of change here", so it was --

Q Are you indicating here that your daughter wasn't actually caught up with the move on move day?

A No.

Q But you were concerned about what were the arrangements for the ward going forward?

A [REDACTED] was an inpatient a lot, quite significantly compared to a lot of other children on the treatment. She was very ill with the treatment itself and she was in very frequently. Again, that's why my concerns were what they were because we didn't have the facilities that we needed, and they're very, very basic facilities that are needed. You're going down six floors to heat up something to bring it back up to eat it.

Q That brings me on to what I was just about to ask you about, Ms Sohrab. I was going to ask you now some questions about your experience on Ward 6A. I think you've

said -- I take it from what you've said at least that your daughter was an inpatient and an outpatient on Ward 6A for the rest of her treatment?

A Yes.

Q When you got to Ward 6A, did you feel that it was a suitable environment for children?

A No.

Q Can you tell us why not?

A It was an adult ward we were told. It was a layout for adults basically. Initially, you know, little things like there was no -- it was a very -- it was made for adults, not for children. It didn't have the kind of child feel or the layout that the Schiehallion Ward had. There was no playroom. There was no kitchen facilities. The reliancing came down to -- in the middle of a corridor, one small table was placed where I think three people could sit down at one point, because it was put against the windows, the glass windows. And there was a child and a parent and another child with a parent standing or something which was an obstruction to drip stands or trolleys, you know, children coming in trolleys, in beds, health and safety wise. It was an obstruction. You felt like you were being an obstruction so we were reluctant to use it.

The facilities there that were

provided for the children were very scarce. Play-leaders were overworked because they were going into rooms rather than one area to work from, where they were trying to accommodate every child. So to even get a play-leader, you were lucky that day. The lovely ladies tried to accommodate as many children as possible but it then became a personal service to each child rather than where children could sit and play together.

Q So are you indicating that their job in effect was made more difficult by this move?

A Yeah.

Q And I think you've indicated there was no kitchen facility for parents, at least when you first moved over to Ward A; is that --

A No, there was nothing on 6A.

Q What was the practical effect of that?

A I recall that -- I'm sure that in Schiehallion parents never used to get meals, and the way that we were told, because we're taking the kitchen away, parents started to get meals. But then they weren't very adequate, whatever they were. So we would go and get takeaways and if you needed to heat something up, you had to go down to the ground floor, locate

a microwave, clean it if necessary because it was being used by staff and other visitors -- and then when you think about the safety of that as well, the microwave is being used by the entire hospital rather than a microwave just being used by the people in the Schiehallion, that's just actually come - - and then taking the food back up to sit and eat with your child.

Q Okay, so that caused some safety concerns as well, having to share a microwave and facilities with the general population of the hospital?

A Absolutely, because the children there in the Schiehallion are immunocompromised and they can pick up infections.

Q Okay. You describe that when you were on Ward 6A you felt that you were in source a lot.

A Yes.

Q Could you tell us about that?

A In source is where you're not allowed to (inaudible) for the child. You're not allowed to leave the room at all for the period that you're in source. A sticker is placed outside the room saying "In source" which, again -- basically you cannot leave the room.

Q And did you feel that you were in source more in Ward 6A than

you had been on Ward 2?

A Yes.

Q Did you form a view why that may be?

A "Infection Control" I was told.

Q Who told you that?

A Nurses, cleaners.

"Infection Control". I remember the words being used: "Infection Control have put everybody in source", and that time when they had started with the medication on the children that gave them diarrhoea and sickness, because of the water issues, I remember.

Q I think you indicate in your statement as well that while you were on Ward 6A you lost the opportunity to communicate with other parents?

A Yes.

Q Is that correct?

A Yes. Basically you were confined to your own bedroom. That's it.

Q What was the effect of that on you?

A It is traumatic because you need that vital support when you're going through an extremely traumatic time in your life. Your child - it's your child, you know, and you need to be able to discuss your

emotions and other things with other people, other adults that are in the same situation as you, and it does help to discuss it. I lost that opportunity. Again, this is the trauma and the effect.

Q Okay, thank you. Now, before we move on to the next part of your evidence, Ms Sohrab, I'd like to think again about the water issues that you've mentioned. Did these resolve when you moved over to Ward 6A?

A (No audible reply)

Q What concerns did you continue to have?

A The filters were always on the taps. I'd never -- before the child case note review that [REDACTED] was coincidentally put on -- have thought that the water would have caused any child infection, serious infections, potentially fatal infections that [REDACTED] received as well. You know, I would never have thought that. But again the concerns were that, you know, hopefully they'll get it resolved, hopefully they'll get it resolved, whatever the issues are.

Q What did you actually observe in terms of issues with water on the ward?

A Bottled water was given out and then we were told it was safe, jugs were given out, and then bottled

water was used again. So it seemed as if are they sure or are they not sure of what is happening?

Q Did you experience any issues with the showers on Ward 6A?

A No, the showers were -- you were allowed to shower. You weren't told that "Don't shower". The shower issues were basically off the actual drainage issues.

Q Was that still an issue in Ward 6A --

A Yes.

Q -- as it had been in 2A? So it was a similar issue?

A Yeah, similar issue throughout the hospital.

Q What, if anything, were you told about having to use bottled water on Ward 6A?

A It was the water issues. That's all it was put down to, water issues.

Q Okay.

A Once it's safe, is it safe, is it not safe, the questions.

Q Ms Sohrab, at paragraph 75 of your statement, you mention one other concern which arose in relation to Ward 6A, I think a bit later on in your experience, and it relates to the type of patients which were being treated in the ward above you in Ward 7. Could you tell us about your concern?

A Yes. We were not told this officially but the reason that -- the way I found out, Covid started and everyone had to go into lockdown. My mother contracted Covid and she was placed in Ward 7, directly above immunocompromised children, using the same three lifts -- or four lifts, is it? Yeah, however many it is down there. My brother was living with his wife that had Covid, his mother had Covid, severe, really bad, and his brother had Covid, who was using the same lift to go up and down, and that's obviously sparking, like, my daughter is immunocompromised. I was told at that point in time that if immunocompromised children get Covid, we don't know the effects. Nobody had enough information at that point. Completely, it was very serious but you have to try and protect the child, don't go out, you know, that type of situation. But yet you think: I know that there's people using the lifts. If you're in a lift, you can't prevent anyone -- how can we prevent someone touching the banister or coughing or breathing those germs that immunocompromised children will breathe?

Q Now, you're indicating that at this time there was no dedicated lift for Schiehallion patients?

A No, there wasn't.

Q Ms Sohrab, before we move on, how would you assess the Ward 6A environment as far as your daughter was concerned?

A Confined to one room and there was no playroom facilities. It was just -- she was lucky -- you were very lucky if the television in your room worked. That was -- you know, you were, "Wow!" And if not, you had to request a tablet for the child to use. She became addicted; we're still trying to wean her off the addiction of using YouTube and, you know, these kind of games and things like that. But that's very common with these children because they had to be confined to a bed. Exercise-wise, again, ■■■■, because she'd regressed, physiotherapy started and I had to try and get her to move a little bit often. Again, moving with a drip stand again is difficult. Playing becomes very difficult because how much -- what can you do confined in one room 24 hours a day, seven days a week? She had cabin fever, I had cabin fever. It became life. Confinement.

Q Thank you, Ms Sohrab.

At this point I'd like to move on, away from your evidence about the wards and facilities specifically and ask you about the infections that your

daughter had when she was in the hospital. For those following the statement, we're moving on to around about paragraph 43.

Ms Sohrab, I'd like to take this part of your evidence just step by step. You've already indicated that you knew infections were a risk throughout your daughter's treatment.

A Hmm-hmm.

Q And you say you were also given some training about identifying the signs of sepsis. Could you tell us a bit about that, please?

A The training I was given because I didn't recognise the signs of sepsis when ■■■■ actually contracted sepsis. I didn't know how to recognise it and then I was told later on it was sepsis. And then actually Dr Gibson explained to me what "rigor" means and how to identify what rigoring is, because ■■■■ rigored several times. How I could, you know, spot these signs by her hands and feet going cold and temperature spiking and the rigoring would indicate sepsis.

Q And what were you to do if you identified any of these signs?

A Come into hospital straightaway and to bring her in as soon as possible.

Q Is that because it was an extremely serious --

A Yes.

Q -- event?

A A matter of extreme urgency.

Q Now, you indicate your daughter had many infections during her time at the hospital and I think you say these were a combination of line infections and temperature spikes. I'd like to come on to look at this in some more detail. I think you've already indicated that when your daughter was first admitted to the hospital, she was fitted with a Hickman line; is that right?

A Yes, that's right.

Q Can you describe to us what a Hickman line looks like?

A It sits in your chest and it's a piece of wire that's like a plastic tube that dangles from your chest, depending on how big or small that the surgeon fits it. It dangles. I was told -- I was informed that they used bags for the children, to bag up the lines and keep them -- I requested them but then I was told because of health and safety they'd stopped providing the bags. Because [REDACTED] had regressed into not walking, she had to relearn how to walk -- sorry, crawl, move her legs, crawl, and then from crawl to kind of, you know, like a small baby does, hold and stand and learn to walk again, so this line would dangle with her or else,

because she was in nappies at the time, get stuck into the nappy, then causing more infections as well.

Q Okay. That brings me on to what I was going to ask you next, Ms Sohrab. As far as you remember, did your daughter ever have an infection in her Hickman line?

A Many times.

Q Can you recall roughly how many times?

A I can't put a number on it but I'll put an average number of ten.

Q How did you know that these infections were linked to her line?

A I was told, "It's a line infection", and then the next was, "Remove the line, insert a new line".

Q Okay. So who would tell you that these were line infections?

A The doctor or the nurse.

Q Okay. Then if there was a line infection confirmed, what was the procedure then?

A The line is -- you're told that your child is fasting and put onto an emergency list for the surgeon to remove the line. It depends on the surgeon's work schedule of when he can get to your child. You know, sometimes it could be first thing in the morning, which is great, but can you imagine a child on steroids, who is

extremely hungry and angry, not allowed water or any food and then, at 4 o'clock in the afternoon, said "Sorry, you're not -- it won't be going ahead today, it might be tomorrow first thing".

Q Then would the process have to start all over again?

A All over again.

Q Am I right in thinking then that each time your daughter had a line infection and it was decided to remove the line, that would require surgery to remove it?

A Yes.

Q Would it also require a further surgery to replace it?

A Yes.

Q That was two separate surgeries each time?

A That's right.

Q Did you form a view about why your daughter kept contracting these line infections?

A I didn't question it at the time but I was just told and assumed that that's what happened with immunocompromised children. I wouldn't for a second have thought that my child would have got an infection in the hospital. No, I wouldn't have thought at the time.

Q And did anyone on the ward ever indicate to you why it might be happening?

A I was just told she's got a serious infection and that's what I still - - not now, obviously, after reading the child case note review, as I've been now more informed, but when it was extremely serious, to the point that it was antibiotics that were so strong, because the germs weren't being removed, that they had to use extremely strong antibiotics.

Q Okay. In your statement you indicate that, at one point in your daughter's treatment, you suggested that your daughter might be better with a port instead of a Hickman line. Now, we've heard some evidence about ports already but I wonder if you could remind us what a port is?

A My knowledge of a port is what I've seen: a small piece of plastic that's inserted into the chest and sealed up so the child can then bathe. With a Hickman line you're advised not to get it wet and keep it as clean and safe as possible, which is difficult when it's dangling about and it's hard then to bathe your child. You can't take your child swimming because you're trying to keep this Hickman line clean and dry at times.

With a port, because it's sealed, you tend to forget it does what a Hickman line will do but it's inside the skin. It's sealed. The channels of

infection are a lot less than what a port [sic] are. It doesn't -- it's not visible.

Q So are you indicating that you felt a port would be better for your daughter because it would minimise the risk of infection in her Hickman line?

A At the point in time when that discussion took place, the kitchens were open and parents were allowed to talk to each other and we had communication. And I was in discussion with parents of a child of the same age and the same diagnosis as [REDACTED] and that child on the same day was due to get a port and [REDACTED] was in (inaudible). So I then questioned that, "Why is [REDACTED] getting a Hickman line? Can she have a port, please, because she'll get less infections?" She was just in with a line infection and I didn't want another Hickman line, I would have much preferred a port going forward.

So when the anaesthetic team came round for consent, I refused consent at that point and I asked for a port to be put in. Yes, I did feel like everybody viewed me as a pest at that point in time, that I'm holding procedures back. But, in all honesty, I'm the only one that can be the voice of an 18-month-old child that can't speak or understand and I am her

protector.

Q What was the response when you made the request for a port?

A Rude, because when the nurses tried to explain to me, I said, "No, well, why is so and so getting a port with the same diagnosis, same treatment going ahead, why is my child getting a Hickman line?" Then there were huffs and puffs and whatever it was. I was then referred to Dr Shazia who took me in and explained to me that a port [sic] would be better off with high-dose methotrexate because it would be easier to administer this medication with a port -- sorry, with a Hickman line rather than a port, which I agreed to because what we do as parents is put our children's lives in their hands because we're not oncologists. I'm not an oncologist. I don't have the medical expertise at all as what they do, the nurses and doctors do. So what came back was, "That's fine". I agreed to it.

I was told -- and the anaesthetic doctor came round and he took a long time, two hours, where I was exhausted at the conversation, is why not to allow it to drag. "If you have to lift her, just keep her lifted". And it's not possible to keep a child lifted when you've got four other children and the child needs to progress in her abilities

in terms of she needs to crawl to be able to walk. It's a need and the line does dangle if she crawls. So, yes, I felt completely defeated at that point in time, then later on learning that the other child that had the port had high-dose methotrexate.

Q Okay. So after you had the discussion with the anaesthetist, did you then agree to your daughter receiving a Hickman line at that point?

A Yes, I did.

Q Okay. Were you concerned about that though?

A I just felt that, you know what, I felt bullied into it, just do it. From then on, I just went ahead with whatever they said. "Okay, fine, I agree with it".

Q I think you say in your statement, and this is at paragraph 50, that after you agreed that, it felt like "putting a lamb to the wolves." Was that because of the concern about infection risk?

A I think it was the main time that I tried to fight for [REDACTED]'s right and everybody's kind of coming at you, "No, no, no, no, you can't have it". Then you question right -- what I was told, I remember now, the ports were finished. Right, if ports are finished for one child, why not my child? Then the explanation was given, which I

accepted more, was that the port -- the Hickman line would be better going forward for the high-dose methotrexate. I accepted it on that.

Q Okay. Ms Sohrab, you also say that during your daughter's treatment she had a number of fungal infections.

A Yes.

Q Could you tell us about those?

A Fungal infections, the main one that I recall when [REDACTED] had a fungal infection, it's just you're told that she's got a fungal infection, not told what source -- where it comes from, how she contracted it. These questions are arising in my mind now, but at the point in time, the question -- you don't get any information back. As I said, I just kind of really accepted what I'd been told: a serious infection.

Q What treatment did she receive for the fungal infection?

A IV antibiotics.

Q Was she kept in the hospital? Was she admitted for that?

A Yes.

Q Ms Sohrab, you mention the independent case note review in your statement and you've mentioned it a couple of times today already and we will come back to talk about that in more detail, but I just want to ask you

a couple of questions. Were your daughter's medical records examined by the case note review?

A Yes, they were.

Q Could you tell us whether the case note review concluded that any of your daughter's infections may have been linked to the hospital environment?

A Yes, many.

Q Overall, how would you describe the impact of these infections on your daughter?

A Basically, so to see the impacts, I can see obviously [REDACTED]'s height isn't as well as her peers. Physically, she's more prone to catching infections and things than her peers. She's just starting to eat now after two and a half years of not eating very much at all, which is great, you know, she is eating now.

The impact of having infections? Traumatized. Being admitted into hospital unnecessarily, where infections could have been really prevented, they should have been prevented. Yes, extreme trauma. Physical, her physical -- impact of her physical (inaudible). Her organs, you know, the long-term impact of how it's going to impact her in the future as well. I don't know. How it's impacted her now I can see; how it's going to

impact her in the future I don't know.

Q Okay, thank you, that's helpful. Coming back to the timeline of your daughter's treatment now, I think you say your daughter's maintenance chemotherapy started in around about May 2019; is that right?

A (No audible reply)

Q Yes, so that was about a year after she was initially admitted, okay. What did maintenance chemotherapy involve for your daughter?

A I was told maintenance was what we were aiming for, "the light at the end of the tunnel" as a nurse described it to me. But for me it wasn't the light at the end of the tunnel, me and my daughter, because she was constantly admitted into hospital even in maintenance.

Maintenance is that where the chemotherapy is administered at home and you come in to -- initially you can come into the hospital quite frequently I remember, initially it's very frequently, nearly every day, every second day, and as and when treatment is required. Going further on in maintenance, you only come into a clinic, weekly clinic which is where you meet the oncologist and have the bloods checked. That's quite further on in maintenance. The initial

maintenance, you're still in hospital very frequently.

Q Okay. I think you say that one of the benefits at least of being in the maintenance phase was that your daughter could now get a port fitted; is that right?

A That was nearly the end of her treatment [REDACTED] had the port. She didn't have it initially in maintenance. She had a line for a long time, and not just one line, again very -- a lot of lines we've had.

Q So your daughter still had Hickman lines fitted for quite a long period of time during her maintenance?

A Yes.

Q Was she at home for some of that time?

A Yes.

Q I think you've indicated though that your daughter was in and out of hospital during that maintenance period?

A Yes.

Q Okay. Ms Sohrab, I'd like to move on now to think about the end of your daughter's treatment and I think you say she was due to finish treatment in November 2020. You say in your statement -- and this is at paragraph 58 -- that she attended the clinic to discuss removal of her line.

Now, just to be clear, was that removal of her line or her port?

A Port it was.

Q Port, okay. So, the removal of her port in November 2020. You indicate in your statement that something else happened that day --

A Yes.

Q -- that you went to the clinic. Could you tell us about that?

A [REDACTED] that day had the clinic actually. We had a clinic appointment and then my routine was, even just after clinic, I would drop her to nursery where she would, you know, play and enjoy her day. We went in and the purpose of that day's visit was to discuss with Dr Shazia the removal of the port. I would have rather remove an external object out of my daughter's body that wasn't necessary, is the way I saw it. If she doesn't need it after treatment, then why should it remain? Dr Shazia's view at that point was that, "[REDACTED] is high risk for a relapse and we would like to leave the port in for a period of at least six months", which, fine, I agreed to because we don't know if a child is going to relapse or not. Fine, we had the discussion. [REDACTED] was due to get vincristine that day which is a medication that is put into the port via injection.

So she had her medication and I took her to nursery. In an hour, the nursery has called saying that her temperature has spiked 40 plus and they were extremely concerned. Her hands and feet had gone cold and they were calling me repeatedly, you know, and then they called an ambulance. Within the hour, it just -- she fell really sick within a very short space of time. I had to rush to the nursery on the motorway, high speed, and I made it before the ambulance did. I didn't want to see my two-and-a-half-year-old daughter being taken by a bunch of strangers in, you know, fluorescent outfits. She would have been very scared. So I made it and I took her to the hospital. I had to tell my children to walk to their granny's house, put them into the street, "You have to walk to Granny's". It was the way it was. Then I took her in for treatment.

Q And were you told what was wrong with your daughter that day?

A Sepsis.

Q Sepsis, and was it related to a particular infection?

A I found out it was pseudo -- they took her blood cultures and two days later, within 48 hours, the cultures came back. I wasn't told formally of the diagnosis, still haven't

been, and it was when I'd called -- we were put into Ward 3A. At that point in time Schiehallion, I was told, was full; and two days later, when I called, I phoned up to Schiehallion to find out kind of what's happening with ■■■, what's her bloods looking like, and I got a registrar. And he said, "She's got pseudomonas, a very serious infection, it could be potentially fatal". That's when I realised how serious. I didn't know what it was, where it came from but that's the way it happened.

Q So do you feel that if you hadn't phoned up that day, you might not have been told --

A No.

Q -- what the name of the infection was?

A What happened then was, a day or so later, we were moved into Schiehallion. Once we found out it was pseudomonas, we moved into Schiehallion. It wasn't full anymore. And once we'd moved into Schiehallion, I assumed for closer observation of how serious ■■■ was, then, no, nobody came round and explained how serious it was. Two weeks of that in there, asking for a doctor to come consistently. And I was told, "It's because you're dropping the children to school". I had to leave to drop my other children to school and

then come back and the ward round is done. Bear in mind the doctors are there until 8 o'clock at night and the rooms -- I'm not allowed to go out into the corridor to go and speak to anybody. We were reliant on doctors and nurses coming into the room to speak to us, but nobody did.

Q So you requested further information about this infection, but nobody came to speak to you?

A Yes, many, many times.

Q Do we take it from that that you were never told how your daughter might have contracted this infection?

A No.

Q Have you formed your own view of that?

A Yes.

Q What is that view?

A When I Googled it, Google has told me it's from a clinical, water-based -- either water or sand. We hadn't been near sand. The only thing was the clinical environment where water was used was the hospital treatment room that she was injected vincristine in. Within the hour of having that injection in her port, the sealed port -- you can't get anything through that sealed port because the skin has sealed over -- when that was put in, an hour after it she fell

extremely sick.

Q Okay, and prior to that, just so that we're clear, I understand that was a day care appointment?

A Yes.

Q So prior to that your daughter was at home; is that right?

A Yes, she was at home.

Q We will come back to the case note review but just to ask you a short question about that now: did this infection in November 2020 form part of the case note review's work?

A It didn't. Outwith their timeline.

MS ARNOTT: My Lord, I'm conscious of the time and I do still have a few more questions for the witness. I wonder if this might be an appropriate time to have the morning break.

THE CHAIR: I'm happy to be guided on it. If you think this is a good moment for a break, we'll take a break.

MS ARNOTT: I think it would be, my Lord. Thank you.

THE CHAIR: We'll break for about 20 minutes. I make it just a little after half past. Could I ask you to be back for 11.55? Thank you.

11:33

(Short break)

11:57

THE CHAIR: Ms Arnott.

MS ARNOTT: Thank you, my Lord.

Ms Sohrab, I'd like to move on now and think about preventative medication. Was your daughter prescribed any preventative medication while she was at the hospital?

A She was.

Q And what were those medications?

A One was Posaconazole, one was Septrin. There was another liquid that was given out to all the children when the water issues came about. I don't recall the name of that one but it's -- she fell very, very sick with it, as did many children. It was consistent diarrhoea and vomiting, very unsettled, very upsetting. That was what Dr Brenda Gibson had said, was, "It's to prevent any sort of infections". "To protect her" was the word, sorry, that was used, "To protect her from obtaining any infections".

Q Okay. I'd like to just explore some of that in some more detail. You've mentioned Posaconazole and Septrin. Can you remember when your daughter was prescribed those medications?

A The duration of the treatment.

Q So from the beginning?

A Septrin was in maintenance. Posaconazole, she would get that in different stages. It was given via IV, so through either Hickman line or her port, and it was pumped into her.

Q And what were you told about those two specific medications?

A Protect. "Protect" is the word that was used, protect her from infection, to protect her. When someone says that to you, you don't question it. And I didn't question it until the one that did spark up, you know, question marks was when it's to protect her from any infections due to this whole water scenario.

Q And who was it told you about the one you can't remember the name of?

A Dr Gibson.

Q Do you recall when that discussion was?

A It was when she was in maintenance.

Q That was some time from around about May 2019?

A Yes.

Q So while she was on Ward 6A; is that right?

A Yes.

Q Was it only your daughter that was placed on that medication?

A All children with either a port or a line.

Q Okay, so all children with a port or a line?

A Yes.

Q Can you remember any more about that discussion?

A No. It was just -- it's not in-depth discussions. You're lucky when you get time with an oncologist. It's basically a two-minute chat and you're informed that, "This is the medication that your child will be put on and it's to protect her from any infections --"

Q And was this a one-to-one discussion you had with Professor Gibson or was this --

A No, it was a one-to-one discussion.

Q I think you've indicated that your daughter had a reaction to that medication?

A Yes.

Q What was that reaction?

A Diarrhoea, vomiting, upset stomach, just really sick all the time.

Q And in your statement you describe what you were told when you pointed out that she was having a bad reaction to this?

A Yeah.

Q What was the response

to that?

A I think most children were, as far as I was aware, having that sort of a reaction, but "It will settle down, it will settle down".

Q Were you told that she had to keep taking it?

A Yes.

Q Why was that?

A Again, we weren't fully informed why they would keep -- due to the water issues is -- I remember. Letters were printed at that time as well and given to us.

Q You received a letter about it?

A Hmm-hmm.

Q Okay. Just to be clear, this was to do with water issues while you were on Ward 6A?

A 6A.

Q During 2019?

A Yes.

Q And what were you told about the medications that were prescribed? I think you talk about this in paragraph 71 of your statement.

A Okay.

Q Were you told that they were strong antibiotics?

A Protective. The ones -- the antibiotics I'm speaking about in paragraph 71 are in relation with the infections, line infections, that she's

had to combat them. And, yes, they're only given in rare cases. I think they're the ones that -- the bugs that are resistant to antibiotics and then they have to up the level of antibiotics which are -- change them about if they're not working, if they're not combatting the infection, you know, check the bloods every single day, depending upon her blood levels, what her numbers are indicating to the doctors. Again, relying -- we're completely reliant on the doctors and their expertise and, as I said before, our children's lives are in their hands. You expect transparency and honesty and won't expect that somebody is going to put your child on a preventative medication that's going to cause them long-term organ damage. That's not fair.

Q I think that takes us quite neatly on to what I was going to ask you about next, Ms Sohrab --

A Sure.

Q -- which is communication at the hospital. Now, you've already, throughout your evidence, given us some evidence about communication, about certain aspects; I want to try and draw that together now, if we could. Could I start by asking you how you would assess overall communication about your

daughter's treatment?

A Dr Shazia is very approachable. She's a real nice person, very approachable, but I only found out from a doctor that we had a discussion, a Zoom discussion with, about MLL rearrangement. And a meeting was supposed to be arranged with Dr Shazia and I didn't receive the call for the meeting to discuss MLL rearrangement because to date I didn't know what -- I don't know what type of MLL rearrangement that [REDACTED] has or had.

Again, the worries, the anxiety for relapse are going to be there forever and nothing will take that away. Her treatment, her diagnosis, the treatment she was put on was like a trial treatment in terms of her leukaemia isn't the most common type of leukaemia, which is the runny, flowy, bloody is what I was told, and what I understand it to be, is the most common form of leukaemia is when it runs through the bloodstream.

[REDACTED]'s leukaemia was in tumour form. The initial lump that I saw was visible, was at the back of the head. When they did the MRI scan, the lumps were inside her neck, in her chest, in her stomach, in her kidneys, in her knees, so it was quite aggressively attacking my daughter.

My worry is without frequent MRI scans I can't see what's happening inside the body. Only lump was visible to me. Otherwise, without that lump, you would never tell that that child had cancer. She was a perfectly healthy, beautiful, chubby little girl. There was no indication of any sickness, illness at all in her.

I'm told, "You'll know, you'll just know", but I won't know, and these worries will be with me forever, you know. Her life expectancy, what damage has the medication, preventative medication now done to my daughter's organs and her life expectancy? Why was she put on? These questions remain unanswered to me. She was put on because of failures on the part of the hospital. That's nothing to do with my daughter. We take our children to the hospital to get better, not to get sicker.

Q Okay, thank you.

How would you assess communication about problems with the hospital building itself?

A There's not really much that they really could do with the hospital building. I remember cladding falling off and workers working outside to repair consistently. Bits would fall off. The garden that was set up, the rooftop garden that was set up for

patients, I never took my daughter up because a parent had said you actually -- it was a porter or a parent, I can't recall -- said, "Well, before, you need to inform a member of staff, they have to go up, collect the dead pigeons and then you can take your kid there".

Q So the rooftop play park was effectively out of use; is that right?

A Yeah -- no, it wasn't out of use. You could go but you had to tell a member of staff to pick up dead pigeons, so I wasn't keen on taking my daughter up there.

Q Okay. In relation to problems with the water system, how would you assess communication?

A Overall, quite confusing. I felt blamed as well at a point in time where, if we were putting teas and coffees down a drain, I do it at home and I don't expect to catch infections from that, so I don't see why we'd be catching infections by pouring teas and coffees or washing your dishes in a sink in hospital.

Q Did you feel fully informed about why that might pose a risk of infection?

A No. I still don't understand what the connection between washing cups and plates and what have you when you're in source

has between a water infection.

Q Thank you. How would you assess the communication within the hospital about the infections that your daughter had?

A Sorry, can you repeat that?

Q Sorry. How would you assess the communications within the hospital itself about infections that your daughter had?

A The words that were described to me when I consistently questioned things is, "She has a serious infection, she has a serious infection". When I communicated with other parents, they knew the exact name of the infection. They were able to use Google as a tool to kind of inform yourself, because you're not gaining information from anywhere else. So, parents were actively, you know, making themselves aware of what's happening to their child and what they have. I wasn't able to do that because I didn't get the information from the sources.

Q Did you form a view about why you weren't being provided with the actual names of infections?

A Yeah, I did actually.

Q What was that?

A I'm not pushy. I accept I was going through quite a personal

traumatic time at that point and I let it be. I trusted them completely with my daughter and I believed that they were working to make her better in her best interest. I did question it, I didn't get the information.

Q So was your impression at least that other parents were having to really push to get the names of infections?

A My impression when I saw other people fight, I was quite scared to be honest. I thought they'd started a battle. I witnessed people being bullied. I don't know how to take names or that, but I'd seen people in tears, I saw kind of cat -- not -- I won't term it as -- like verbal disagreements where there's nurses on one side, parents -- not parents, but a parent on another side, and it was consistently. And I'm like do I have the time or energy to be involved in something like this, you know? It was tough going.

Q So you've described it as "a battle" --

A A battle.

Q -- the other parents were having to have to get this information?

A Yeah, and I think we were in a battle enough. When your child's got cancer and you've got four other children to look after solely, for me, that was enough of a battle.

Q I take from what you've said, Ms Sohrab, that you felt if you got involved in one of these battles, it might affect your relationship with the doctors and nurses on the ward?

A I think it has.

Q Okay. Ms Sohrab, you've already mentioned that your daughter was involved in the independent case note review and I'd like to explore that also further with you. When did you first hear about the case note review?

A I was sent a letter. I can't remember at what time. It was quite significantly before we got the reports in. ■■■ was part of the child case note review because she was treated in the hospital for a certain amount of time and "We've found infections that are linked and we're going to explore these infections". That's what I recall the information to be, but it was various, various letters many, many times. It was good information in respect of the child case note review but, when it came through, it was quite shocking and very, very traumatic and disturbing.

Q Did you receive an individual report --

A Yes.

Q -- about your daughter? I wonder if you could outline at least

what that concluded.

A It concluded -- sure. I don't have it in front of me but at least four infections, at least, of many infections that were linked to possibly - - the words weren't determined -- they did not determine anything. It was "possibly", "maybe"; there was no definitive language used which would be, I think, one of my main concerns. "Possibly", "maybe", "could be" was the language that was used, linked to the hospital environment.

Q Can you recall about the specific infections that were mentioned, whether there was a possible or probable link to the hospital environment in this case?

A I can't remember the names of the infection. It's on the child case note review, I don't know if that's available to everybody but you can --

Q Okay. But was your understanding from the report that there was at least the possibility of some link between the hospital and the infections that were mentioned?

A Yes, absolutely.

Q Did the individual report that you received comment at all on the impact on your daughter from these infections?

A It did, yes.

Q What did it say?

A Significant impact in terms of obviously stays at the hospital, each time requiring at least about a two-week extra stay at the hospital, which in time you're having to think about, you know, the impact not just on [REDACTED] herself, her physical well-being, her emotional well-being, the person who is staying with her, be it myself, my parent -- one of my parents, or her four other siblings. So the impact was severe on every case for everybody because these four other children are being displaced from their home to another environment or, if I'm staying, they were displaced. If I was not staying, they were in their environment but I'm still running around, going to the hospital, coming back from the hospital, they're going to the hospital after school. So, yeah, it was very much a part of our lives, our daily lives.

Q Thank you. That's very helpful. In addition to the prolonged admission to hospital, did it conclude whether the infections had impacted your daughter's treatment for cancer at all?

A [REDACTED]'s treatment for her cancer has not been concluded because of the admissions, prolonged admissions. [REDACTED] has not received the full treatment for what she was due to

receive for that period of time of chemotherapy. I assumed that the period, the missing gaps of when she's had infections and chemotherapy is stopped -- when a child has a spike, a temperature spike, the chemotherapy is stopped automatically -- my assumption was it would be added on at the end. It's not been added on at the end.

Q So your perception is there were actual gaps in the chemotherapy that your daughter --

A She's missed, yes, ah-ha.

Q Okay. How did you feel when you read the individual report for your daughter?

A Traumatized, honestly, because you think why didn't they tell me? Why didn't they tell me all this at the point in time? Look what she's actually going through and I'm told it's a serious infection and it is possibly linked. And it's unfair that, again, as I said, you know, in the 19 -- in the early days people used to take their children or their sick people to beaches and things to get better; you're taking them to a hospital and bringing them back sicker. That's not fair on a young child, on an adult, on anyone. It's unfair.

I was. I was very angry, I was upset, and shocked as well. Not

happy because, on the very same day I received the report, [REDACTED] had to go to hospital for a clinic appointment, so yeah.

Q I think you've just probably given us the answer to this but did you feel that any of the information you saw in that report had previously been provided to you?

A Serious infection, any of the information -- at the time she got the infection, full information wasn't provided to me. I would say that because, as and when the nurses were coming in, I knew what they were doing but I didn't know why they were doing it. I knew her antibiotics had been changed but she's fighting a serious infection because she's not reacting as well to the antibiotics she was on. So it's that kind of going-with-the-flow type of information rather than a full outline picture which I received then --

Q So did you feel that the case note review provided you with more detailed information than you'd been provided with?

A Oh, yes. Absolutely, yes.

Q Would you have preferred to have received that information at an earlier stage?

A Yes. Actually when events were taking place, yes,

absolutely. You want to know when I questioned, what is it she's got, what is it, what's the name of the infection? And, no, I hadn't. "Serious infection" or "We'll get back to you" or this or that. Or when I asked to speak to microbiology when [REDACTED] got pseudomonas, I was told, "Because you were out, they hadn't -- they were here and then they've left", and we didn't get a chance to meet or discuss.

Q You didn't get a chance to meet or discuss the pseudomonas infection with the hospital staff; is that right?

A Yes, ah-ha. Not even a doctor actually because I requested and requested time and time again. I didn't know what's happened. I remember going up and down in the ward and that same room was used for treatment with immunocompromised children, but what if -- you know, the fears, and I'm thinking that's public -- that's other people's children, not just my child. It's everybody's children going in there who could end up potentially very sick, a potentially fatal bug is what the doctor had said to me. And obviously it's ringing alarm bells but what could I do? What can I do? Nobody is willing to talk to me about it.

Q I think you've already told us that the November 2020

pseudomonas infection was not included in the case note review.

A It's true.

Q How did you feel about that?

A Not happy because, if that's a water-related infection, then in my mind it tells me there's still water-related issues in the hospital which is still being used for treatment of children, and quite scary in fact because there is immunocompromised children and adults in the hospital who could potentially catch that infection then.

Q Were you told why that infection was not included in the case note review?

A Because the time period has lapsed from the case note review.

Q So you'd missed the cut-off effectively?

A Yes, ah-ha.

Q Okay. Overall how did you feel about what the case note review said?

A The language used wasn't definitive language at all. It has outlined the fact that there is possible links to the hospital environment with ■'s infections but it does not say, "Yes, definitely", or "No, we can't". Because they weren't there at that point in time, I understand from that respect that

they cannot use that because they weren't there and they can't establish what happened in the past. They have tried their best to, but again the issue would be with the language used. It was very informative. It is very informative, quite scary, and very shocking.

Q You say the case note review tried their best to find out what happened. Did the report that you saw indicate any obstacle that was in their way in terms of finding out what had happened?

A For me personally, when |'s medical notes were requested, they were not handed in because of an error to the spelling of the hospital or something very minor. To me, it felt like very petty. Why not just give -- there's not an "i" or you've missed out the word "royal" or something, then you know the child has had treatment here, you know who the parent is and it's been signed and requested. And the form was lost on one occasion I was told and another occasion the spelling was misspelled or something. So yeah.

Q Now, just moving on from that now, Ms Sohrab, you mention in your statement two Facebook groups which I think were related to the hospital. Could you tell us what those

two groups are?

A One is the Schiehallion Parents Group which I was added onto by a fellow parent and it's where parents -- we go on and discuss our concerns and basically are able to link in with each other.

Q Did you find it helpful?

A I did. It was helpful, especially when you're in source isolation and you can't meet people face to face. Absolutely, yes, it does help you. For example, I aired a concern that [REDACTED]'s hair fell out after treatment. After her chemotherapy treatment had finished, my daughter's hair was still falling out. I was very concerned because in maintenance I had seen children recover so fast that their hair is back and they're looking glossy and healthy. [REDACTED] was not one of these children. She was very, very sensitive to the treatment. Her hair kept falling out. She was very skinny, not eating, again with the water boluses, the feeds. So, obviously, I was concerned so there were people who were able to answer me in respect of the treatment, you know. Some other parents had seen that with their children so it was helpful for me to see that. And when parents post up of their children getting better in the future, that brings out hope that, you

know, my daughter hopefully will recover from this and have a long life.

Q Okay, thank you.

I think you mentioned there was another group on Facebook set up, I think set up by the health board.

A Yes.

Q Did you find that group useful?

A I didn't go into that at all.

Q Why did you not join that one?

A Because I felt that, if parents are discussing things with each other, that's to do with parents and their experiences, not for Big Brother to monitor.

Q Okay, thank you. Ms Sohrab, we're moving on to the conclusion of your evidence now and I'd like to ask you to reflect on the impact all of this had on you, your daughter, and your family. Your daughter was going through very difficult treatment for cancer which must have had an effect on you. You've also described a number of other issues connected to the hospital environment and infections which you had to deal with during this time. What additional impact would you say that these other issues had on you?

A Emotionally very draining. I had to come to a point that

I had to try and detach myself from my own child in order to function because there was no way of functioning if you become emotionally -- I was on a constant flight and fight mode, constantly. There was no in between because I had to be there for my child, not just my child who was sick, and trying not to deal with my emotional impact on that, but to be there for my other children as well. So, yeah, I was trying to just be -- you know, knowing that my parents are there, they're looking after her, the hospital staff are there, trusting, and did I do the right thing by trusting? Now I question myself.

Q And what, if any, impact would you say these other issues that you were dealing with had on members of your family?

A Members of my family in terms of my children or my parents?

Q Let's start with your children.

A Emotionally very traumatised, all of them. Very traumatised seeing their -- they'd be going to school and talk about obviously their sister's sick. They would spend summers in with [REDACTED]. I remember, when it's blaring heat outside, sun, these kids are inside playing, doing pictures with their sister.

Where are we going today? People are taking their children to the park but I'm taking my children to the hospital to be with their sister. It became daily life routine for us. A lot of uncertainty for my children, not knowing where they're going to stay, if they're staying at Granny's on an airbed or they're staying home, not knowing when your mum is going to have to get up in the middle of the night and run and take you all and arrange someone somewhere to come and stay with you.

I can't imagine the trauma that my children have experienced.

Leading to one of my daughters is --

[REDACTED]
[REDACTED]. Trying to focus on getting better.

Now one of my daughters, a teenager, [REDACTED]. I don't know whether that's partly normal or partly due to trauma that she's experienced, significant trauma. Yeah, I would -- all of my children have been severely impacted by their life experience from their sister, yeah.

Q And what effect would you say it's had on your parents?

A A very difficult effect for them because I've become dependent upon, reliant upon family whereas I really shouldn't have. Being a single parent, I felt that there was not really

very much resources that I could turn to. I tried social work, I was told the only way forward for my children would be put into foster care when [REDACTED] is admitted in hospital. I wasn't having that. That is, to me, even more trauma for my children. Four of my children placed in different homes throughout the city, I can't bear to imagine trauma, the excessive trauma, unnecessary trauma placed on them. I was not going to do that. So, yes, I was put to ask family for help and they did come out for my children, absolutely, even if we had whatever issues but they absolutely came out for [REDACTED], they did help.

Q Okay, thank you.

Finally, Ms Sohrab, what impact do you think all of these issues that you've described had on your daughter?

A On [REDACTED]? We went into hospital on Tuesday and [REDACTED], when you see her now, you will never ever think that this child has ever had the experiences that she has ever had. She is such a smiley, happy, dancey -- even with sepsis, we'd said, "Well, [REDACTED] likes to dance", and she was kind of -- she heard what was said and her little shoulders started to move. So she's a happy, bubbly, four-coming-up-five-year-old little girl, loves dancing. But

the actual impact is she's lost her defence mechanism. She's lost the fact that, when you talk to a child, they're immediately strange to you. They're immediately, you know, stranger danger. [REDACTED] doesn't have that anymore. People don't realise that. People enjoy the fact that this child is responsive and happy to meet. They don't realise that this child has lost that complete stranger danger. She doesn't recognise a stranger. She'll smile and love and cuddle anybody. To me, that's dangerous because she's a child and she needs protection. She's vulnerable.

That; her fears of the colour blue, extreme fear of it. She went to hospital and as soon as she got into the doctors' bit, she was fine with the nurses, she was chatting, a bit scared. Literally, "Shall I take your blood?" She said, "No", and pulled her hand back. But fear of the colour blue has -- and I had mentioned it many times before, that if we could have like bright colours for the children. It's a possible suggestion. Different colours, you know, with your name badges on so we know you're staff. But it's all blue, everyone's blue, because everyone in blue pins her down and hurts her. So psychological impact, I don't know how long that's going to take to come to

terms with.

I don't know in future how it's going to impact her, her learning, her ability to do things. In fact, physically she'll get tired. She's a lot smaller than her peers, she's tiny. Small but mighty.

Q Ms Sohrab, I don't have any more questions for you. So before we conclude, is there anything that we've not said today that you would like to say now?

A I would just like to say that we trusted the hospital with our children's lives, and we did not expect -- I'm saying this on my behalf. I personally did not expect my child to go in and walk out with a potentially life-threatening bug on one occasion and on other occasions have infections linked to the hospital. I did not think that the cancer won't kill your child but infections will. You understand later on because they're immunocompromised, infections are potentially dangerous, but those infections, why were they picked up in hospital?

These things need to be reflected on, not just for my child but for the children of Glasgow, Edinburgh, for everybody's children. And it's very, very important that we hopefully learn from this experience and hope to

improve it for everyone's children going forward.

MS ARNOTT: Okay, thank you.

My Lord, I don't have any more questions for Ms Sohrab.

THE CHAIR: Thank you very much, Ms Sohrab. That's the end of your evidence. Thank you for providing the witness statement which is part of your evidence and part of the evidence before the inquiry and thank you for coming today and providing your evidence orally in addition. Thank you very much, you are now free to go.

A Thank you. You're welcome. Thank you for having me.

(The witness withdrew)

THE CHAIR: Right. We have another witness this afternoon?

MS ARNOTT: That's right, my Lord.

THE CHAIR: Yes. Well, we'll rise and sit again at 2 o'clock. Thank you.

12:30

(End of Morning Session)