SCOTTISH HOSPITALS INQUIRY

Hearings Commencing
20 September 2021

Day 22
Friday 5 November
Afternoon Session & Closing Remarks

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(NB: Please note that the witness attended via videolink and at times is difficult to hear due to poor connection)

12:00

THE CHAIR: Our next witness is Ms Cunningham, and I'm looking at a screen which does not have a video feed, but it may be that Ms Cunningham is able to hear me. Ms Cunningham, good afternoon. Are you able to, first of all, hear me?

THE WITNESS: Yes. I can hear you and see you.

THE CHAIR: Right. Thank you for that. Other piece of information, which is precisely what I was going to ask you. We now have you onscreen. If, during your evidence, there's any, first of all, technical problem at your end, no doubt, you'll tell us, but our technical people, I suspect, will be on top of it. They'll know what's happening. The other thing is, if at any stage you want take a break, just tell me and we can take a break. Now, I think you're happy about taking the oath?

THE WITNESS: Yes.

Ms LOUISE CUNNINGHAM,
(Sworn)
Examined by Mr DUNCAN

THE CHAIR: Thank you very much, Miss Cunningham. I'm now going to hand over to Mr Duncan, who I think you've perhaps had the opportunity of meeting, albeit not directly. Thank you. Mr Duncan.

MR DUNCAN: Thank you, my Lord. Hello again, Ms Cunningham.

A Hi there.

Q We always start with some formal questions. And if you'll forgive me, I'll do the same with you. And so, can I just begin by having you confirm you are indeed Louise Cunningham, and you live with your two sons in the west of Scotland, is that right?

A Yes. That's correct.

Q And you've joined us today to talk about your daughter, ███, who I think was born in ███ , and who passed away in █████, is that right?

A That's correct, yes.

Q And is that picture of ███ we're seeing behind you?

A Yes.

Q You've provided us a detailed statement and a detailed timeline, and are we right in understanding that you are content that that forms part of your evidence to the Hospital Inquiry?

A Yes.

Q Thank you. And am I right in understanding that you've got a copy of it beside you?

A Yes, I've got it.

Q And can you hear me okay?

A Yes. I can hear you perfect.

Q Okay. If we just begin, we're going to go through the story of ███'s treatment at the Royal Hospital for Children in Glasgow in 2017. But before we get to that, let's begin with diagnosis. And I think we can see from your statement that ███ hadn't been well for a spell, I think, in March 2017 and you were backwards and forwards to the Royal Hospital for Children.

A Yes. That's correct.

Q If it's possible to do so, Ms Cunningham, I wonder if you could just tell us a bit about that and maybe just take us up to the point where you get ███'s diagnosis.

A Basically, ███ took unwell towards the end of February, the start of March, and up to that time had one admission, where we went in and we were discharged straight away, saying that she had a viral-type infection. On the second occasion, I took her into the hospital. She was admitted and she was in the CDU unit for two days and, basically, they were still saying that, at this point, a viral infection could last over 14 days. So, again, we were discharged from the CDU, and I was then told, it was still a viral infection. The only thing they could see was ███'s haemoglobin was slightly low. So, we came home, but nothing improved. She was just lying about, very, very lifeless. She wasn't eating, wasn't drinking, was just-- She looked like a ghost. She was so peely-wally.

So, I took her back up to the hospital on a third occasion, and again they says, "Oh, we think it's still a viral infection." But I refused to leave that time. I said, "No. I think there's something more going on." And they were making it out that I was being an overprotective mother, and it was a viral thing. And I said, "No." I said, "I want to see a different doctor." So, at that point, they admitted us up to Ward 2C. And they took bloods and things, they kept saying they think it was still viral.

And then later on, it was in the early the morning of 17th that a nurse and doctor had arrived into the room to say they had to take ███ for a CT scan, and an x-ray to be done. And I questioned why, and they just said,

"Well, we found something in her bloods." And I says, "What do you mean you found something? Why are we doing this at this time of night?" And I said, "Is this something serious?" And basically, the doctor had said instinct(?) what we found in the bloods, it can be quite serious.

So, we went to the CT scan and obviously the x-ray, and then they'd come back into the room in the morning to say that the scan had showed that ███ had pockets of blood in her head. So, they had said that "Has ███ had any trauma to the head?", and I said "Well, she bangs her head all the time". And he then says to me, "No, I mean this would be trauma from a car crash." And I'd said, "Well, no. You've got her medical notes here, so you should be able to see."

But they also found that her liver looking enlarged in the x-ray, but it turned out that she didn't really have any platelets in her body that was basically clotting the blood, so the blood was just floating about. There was no clotting anywhere, so that's why she had pockets of blood in her brain.

On the morning of the 17th, we were taken straight down to ultrasound at nine AM in the morning. Went

down to the ultrasound, and basically, at that point we went back to the Ward, went up to 2C, and there was two doctors and two nurses asking me to step into a room across from where

███ was. And they basically told me that they'd found two masses within ███'s abdomen area: one in the liver and one in the gland above the kidney on the left side. So, basically, they say to me that they had to move me straight through to Ward 2A, which was just directly through from 2C. And I said, "Well, what's that?" And they said, obviously, "It's the oncology ward." But obviously, you know when you hear the word "mass", you know exactly why and what it is.

But we get taken through there. It was quite strange. ███ had basically deteriorated so much. It was as if she knew that there was obviously something wrong with her. It's as if she knew that people knew, and she deteriorated quite quickly. So, basically, it was a Friday, so they didn't want to start doing any tests over the weekend. So they basically just kept her comfortable. They ended up putting her onto a morphine pump because it got to the stage where I wasn't even able to change her nappy without her being in pain. So, she was put on fluids, she was given

transfusions, she was given platelets. She also had to do urine samples and stuff like that.

So, first thing on the Monday, basically, they took her away for five and a half hours, and she got her scans done. She got a DMSA scan, an MRI scan, she got lumbar punctures done, which basically they came back-- And the doctor had basically said to me the way ███ was acting and what they could see so far-- Obviously, they had to wait on biopsy results and the urine results. Neuroblastoma is a hard cancer to detect. It's most common you can find it in a DMSA scan, and in the urine sample. Basically, the doctor was saying to me that ███ was getting worse. And he basically was saying we don't have ███'s results, but his opinion of what he'd done all his life, he said that he thought she had Stage Four neuroblastoma cancer, and basically, on his opinion was to start treatment straight away because would have probably passed away while waiting on the biopsy results to come back.

Q Yes. And I think we can see from your timeline, Ms Cunningham, that that was about the 23 March.

A That's correct.

Q I think that the consultant was saying his suspicion was this is high risk neuroblastoma, Stage Four. We need to start chemo immediately, is that right?

A Yes. That's correct.

Q And I think the diagnosis was, in fact, confirmed on the 21st.

A It was confirmed that she had Stage Four neuroblastoma cancer.

Q And I think ███ was two years and eight months at this point, is that right?

A Yes.

Q Now, what I'm going to do in a minute is have you take us through ███'s treatment on Ward 2A, and some of the key events. Before I do that, I want to ask you a little bit about Ward 2A. Now, we've had quite a lot of evidence about Ward, so I don't need to go into it in too much detail, but you do mention a couple of things that I would be interested in hearing you tell us something about.

Now, one of the things that you mention in your statement is the parents' kitchen and you indicate that you found that quite a useful place for you to go. Can you maybe tell us a bit about that?

A Basically, the first day ███ went for her scans and stuff

like that I was told to leave the hospital because she'd be away for a while, but the parent kitchen was really good because you would walk along, and you would meet families that you didn't know. And obviously, kids weren't really allowed in the kitchen, so it was a good place to go if you needed to let off a wee bit of steam without your child seeing you being upset. And there was other parents there that you could speak to. And they were obviously in the same situation as us obviously. Some days I would walk in, it would be a new family that was there, and I would speak them through things.

But obviously, when I first arrived in the Ward, there was one particular man I met who basically spoke me through what was going to happen in the ward, and stuff like that. And it was a useful place to go because you could go there and you could sit, you could cry, you could have a cup of tea, just basically your own headspace away from the room that you were actually in within the ward.

Q And you tell us a bit about this man, I think, in your statement. A man who was or who had been a ███, is that right?

A Yes. That's correct. His ███ was in the ward as well.

Q And I think you also say to us that this was somewhere you could just go and sit and have a cup of tea or a cup of hot chocolate and just unload with somebody else.

A Just basically unload, yes. Even if it was funny ones, if there was a family with a new room, you could speak to them, because obviously, we were all in the same situation and we all wanted to offload, but we didn't want to put it on our own families. So, offloading to each other helped because obviously didn't want your family to see how upset you were getting, and what predicament we were in, you especially didn't want your child to see it. So, being able to go to a room where there's other parents there to offload in the same situation was a lot easier.

Q Another thing that you mention in relation to Ward 2A, and I think this is probably something that was more to do with ███, there was a bath on the ward. And was that something that ███ particularly liked?

A Yes. Because it was-- She used to call it her "boat". It was a huge, huge bath. And there was buttons on it so that it could raise up off the ground and go down. And it was really, really big. ███ wouldn't even say, "Can I go for a bath?" She'd

say, "Can I go for my boat before my bed?" Because that's what she called it.

Q I think in your statement she was obsessed with the bath, is that right?

A Yeah. She was never out it. She was never out it. She'd have been in it all day if she was allowed.

Q Now, let's move on and have you take us through the timeline of ███'s treatment. And let's start at March. What sort of chemotherapy treatment was ███ on?

A ███ started with an eight round of rapid COJEC chemotherapy, which was four different types of chemo. They would last three or four days at a time. So, she would have eight rounds of that to start off with. And when she got to the end of them-- obviously, it was making her quite unwell, and things like that with sickness and stuff. But once we obviously finished her eight rounds of her rapid COJEC chemotherapy, they done her scans to see that, basically, it had shrunk her tumour, but not enough to go in and operate. So, we have to add in two rounds of TDB chemotherapy.

Q I will come on to that. If we just stay in March at the minute, she had something called, did you say, "rapid COJEC"?

A Yes. Rapid COJEC chemotherapy.

Q C-O-J-E-C, is that right?

A Yes.

Q Yes. And how was that administered to her?

A It was through a Hickman line.

Q Now, something that we'll come onto later is that you indicate that ███ had a number of issues with her line throughout her care.

A Yes.

Q But are we right in understanding that, in fact, even right at the start, she experienced an issue with her line, is that right?

A Yes. We basically got-- Her Hickman line was administered for her to start her first round of chemotherapy. Basically, ███ was still very unwell, which the doctor was a bit confused about, because usually when they get chemotherapy into them, it should pick them straight up. But ███ was still lying about quite lifeless, not wanting to eat, not wanting to drink. And then it turned out, they found that she had an infection within her line. Before we were able to even move on to her second round of

chemotherapy, ███ had to go for a second surgery to get the line removed. Then we had to wait 48 hours for them to administer another Hickman line, which basically went through the neck into the main artery of the body.

Q Yes. Now, if we then move into April, do you recall that there was a point in April where the Ward was effectively shut down or locked down?

A Yes. We were basically put on lockdown. No one was allowed out. We basically weren't allowed to leave the ward. We weren't to leave our rooms. We weren't allowed to go to the parent kitchen because of something called the rhinovirus. Obviously, I'd never heard of it, but the ward was put straight on lockdown. We weren't allowed out our rooms, we weren't allowed anywhere. Nobody was allowed to attend the ward. So, that was us isolated in our room. We couldn't communicate with other families, we couldn't with our own families. I wasn't allowed to see my other children. And this went on for about two to three weeks, if I recall.

Q Now, I've got a couple of questions about that. Was it you who was with ███ on the ward?

A Yes. I was there the whole 10 months. I never left. I was there every single day and night that was in the ward.

Q And the other question I was going to ask is why is it you are able to pinpoint this to April? Why is it you're able to recall this event in particular?

A Just because our family had come over from Ireland. An auntie had come over, and basically, they were coming to-- They hadn't actually met ███ 'cause-- And they were coming over to meet her and basically, the day when they'd arrived over Ireland, the ward had been shut in, basically, with signs outside saying there was no entry. Nobody was allowed in; nobody was allowed out. So, ███ never got to meet her family at that point in time because it was shut down. So, they'd travelled from Ireland at that point. So, that's how I know it was pinpointed in April.

Q Thank you. And what was the effect on ███ at this stage, about the two of you effectively being locked into the ward for this period?

A It just wasn't right because she was used to being able for me to take her for a walk in her pram up and down the ward, or carry her with her drip stand. She was able to go outside the room and it was too

much for her. She still was pretty unwell at this point in time. From a two-year-old's point of view, I've been made to stay behind a door without being able to step a foot outside of it. Even opening the door, the nurses were ushering you back into the room.

So, confining a two-year-old to one room is extremely hard. It's really, really harsh because she didn't understand why she wasn't allowed to see her gran or her brothers or anything like that. So, she would be asking for them, and I'm having to say, "There's a wee bug in the hospital, and we need to stay in the room." But a two-year-old, she had no recollection. She didn't know or understand what was going on, but obviously the effect on myself at that point was quite stressing because I wasn't able to take five minutes myself out of the room, just to get a cup of tea or for my mum to sit with her for ten minutes for me to go downstairs to go and get something to eat or whatever. It was quite hard.

You were having to buzz constantly for somebody to say, "Could you do this for me? Or can you do that for me from the parent room?" We weren't allowed out, but you felt as though you couldn't buzz because there was other on the ward who were extremely unwell, and you didn't want

to take, in effect, away from the kids that really needed it by buzzing for the nurses all the time.

Q So, you and ███ are literally stuck in a room for, what did you say, two to three weeks?

A Two to three weeks it was, yes.

Q And the only people coming into the room would be----

A Would be nurses and the doctors. Yes.

Q And ███ would have no access to the playroom or anything like that, is that right?

A No. No access to the playroom. There was no access even beyond our door. Even if you opened the door, you were getting in trouble. You need to keep the doors closed at all times.

Q And you would have no access to the parents' kitchen, and therefore no opportunity to make food for her.

A No. So, ███ was quite a fussy eater. So, see when you were getting given the same food every night, it got to the stage where she wasn't wanting to eat because it was just the same scenario. She wasn't getting a different option, whereas when I had use of the parent kitchen, myself and a few of the families that

I'm quite close with, you would go to ASDA or whatever and get stuff in that you knew that she would eat. Because the food scenario, it was the same food day in, day out. So, they were getting fed up of it.

Q And something that you've mentioned is also about her not being able to see other family members. Was that an issue for her?

A It was because she was very close with her gran and her brothers and her auntie and things like that. So, the fact that her cousins and her brothers and her aunties and her gran and her dad and that weren't allowed into the ward, she was finding it hard. And when we were coming off a video call, she was getting upset, and then I'm trying to prevent myself from getting upset when I'm trying to explain everything that's going on, because the last thing you want to do is for your child to see you sitting in a room crying and upset because it's not fair for them to see that.

Q And again, just thinking about these early weeks in ███'s treatment. Did you notice anything else happening as regards the rooms?

A Basically, when we were in there, there was a lot of deep cleaning. It started to be done within the ward. They started moving us

rooms to clean them and every other day we had infection control that was in the ward. And basically, when I was admitted to the ward on 17 March, we were told to, basically, make the room our own. So, I'd brought ███'s quilt and her pillows from home. I brought her teddy. She had a few of her toys and stuff that she wanted. Obviously, she was getting balloons and cards and stuff like that. And then it got to the stage where infection control were never out of the room. Your room was getting cleaned two to three times a day.

We were then told that everything we had within the room had to be sent home. We weren't to keep anything within the room which after them letting the kids get comfortable with in a room and having their own stuff, to have to send that away and then not have it, and you get to keep one or two things, was quite hard on them. We had-- any drawings that had been done, any paintings, everything was sent away. We weren't allowed anything. She was allowed to keep a couple of teddies, and that was it, whereas before she had her wee pram and doll that she would go up and down the ward with. Everything had to go.

At that point, the cleaning team in

the ward started bringing in plastic drawer sets. And put one in the bathroom and one was in the room. They said that nothing was to lie on the floor. We weren't allowed any of our toiletries sitting about the bathrooms, everything had to be put away. And then that's when they started moving us from room to room. And you would see the rooms getting deep cleaned. They would put plastic coverings over the doors, so everything was completely closed all the time and they were doing deep cleans and that. I think ███ was in every room in that ward with being admitted(?) and being moved to with the rooms being deep cleaned.

Q And when you say "infection control" or "infection prevention control", are you meaning cleaners? Are you meaning doctors? Are you meaning----

A No. No. Actual infection control. At one point, the sister of the ward, the head nurse at the time, she had come in and said, "Oh, infection control want you to send everything away." And I was like, "Send everything away?" and she went, "Can't have all this within the room." And I was like, "Well, it's just what we were told to do and make the room as comfortable for ███ as possible." And

she was like, "No, no. infection control want everything away." They were on the ward every day. They'd check your rooms every day.

And if there was anything lying about, even like my mum was doing washing. Obviously, I stayed close enough to the hospital, that I didn't need to go to the CLIC house. So, my mum was doing my washing and things, she was bringing it back up in a case and stuff. You weren't even allowed a case to be lying on the floor. You weren't allowed nothing lying about that room at all. And if you did infection control would basically be on at you every other day.

Q And did you yourself see the infection control personnel?

A Yes. I'd seen them on numerous days. They were in the ward every day. They would walk by your room; they would look in your room. Every day they were on the wards.

Q And did they appear to be cleaning staff or medical staff or something else?

A No. They must have been-- They weren't cleaning staff. You had the same cleaners every day. You had your cleaners through the week, you had your cleaners at the weekend, but they were in their suits

and stuff. So, you knew that weren't just there as being a cleaner. They were there and they were walking about with a clipboard and notes every other day.

Q And you indicated that, effectively, ███ had to give up some of her belongings, is that right?

A Yes. She had to basically send everything we had in the ward away. Any pictures, her balloons that people had brought her up, get well cards, everything had to go. She was allowed to keep one doll and two teddies, and they had to sit on her bed. Everything she had in the room had to be sent away.

Q I mean, up until that point, just thinking about what you just said, had you done everything you possibly could to make her room feel like her own room at home?

A Yes. Basically, ███'s treatment was going to be a foreseeable treatment. So, we initially went into the ward, we knew we were going be in there until at least June, so that would be three and a half months. We were there the whole time, and ██ had her stuff there. She had her wee pram and her doll, her toys that she liked, she had her teddies on her bed.

And basically, we're told

everything had to go. ███ at that point started getting upset because, when they were doing deep cleans, you found quite often that the playroom would be closed because they were doing cleaning, so she never really had stuff in her room. The (Inaudible) team were because they would bring the arts and crafts into the room for them to do, but it's not the same as being able to go to a playroom and be amongst other children and be able to have fun. Because when infection control come on the ward, it was just a totally different place to be in. It didn't feel like a happy place where you're meant to make your kids feel comfortable. It was more like a stricken area which, in a children's ward, it shouldn't be.

Q Yes. So, for those who want references in this statement, it's paragraphs 27 and 28 and 75, and we're not going to ask you to turn those up just now, Ms Cunningham. But if we imagine the room before infection control arrive, are we to picture something that had balloons up, had cards, had toys, had a pram with a dolly in it, is that right?

A Yes. And she had her teddies all along her bed, her favourite teddies. There was her pictures up on the wall that she painted and things

like that. They were all round. So, the room was basically like her own wee room because she had all her toys and her teddies that she loved.

Q Yes. If you had to put a percentage on how much of that stuff had to go, what would it be?

A About 98 per cent. Basically, she was left with a doll in her bed and a few teddies. Every bit of paper, card, balloon, everything had to go out. Her colouring books had to go because the infection within the ward, they said all of this stuff could have been contaminated. So, I had to get someone to come and collect it and take it all the way home.

Q How much of it was allowed to come back eventually?

A Basically, you never really got to bring much of it back at all. If anything to come into the ward, it had to be brand new, basically, within a box, it hadn't been used at home or anything like that. Basically, we weren't allowed any clutter within her room whatsoever.

Q At any point before ███'s inpatient care concluded, did her room go back to the way it had been before?

A The only time that had a few stuff in her room was through transplant because we were isolated to the one room, and basically, it was the John O'Byrne Foundation who had bought ███ lots of new dolls and paint and colouring things and stuff like that. But that all had to be brought in brand new in the box. If anything had been opened, it wasn't allowed in. And then the minute we moved out of transplant, and we moved back into a normal room, it had to go again.

Q Was there ever any explanation for what had happened in ███'s room?

A No. We'd ask on a few occasions like, "Why do we keep getting moved rooms?" And we were just told other people needed the room". But then when you were seeing that rooms are being closed and getting cleaned out like it was industrial cleaning, but it wasn't-- the smell of the cleaning stuff wasn't normal cleaning products. It was strong smelling, so I think we were in nearly every room within the ward at some point, apart from the teenage unit.

Q Yes. Now, after this, again, still thinking about these early weeks, March/April, after that, did isolation become quite a regular feature of ███'s care?

A Yes, it did. The isolation, obviously, when they were on, I had to

actually have a debate with my consultant to speak to infection control because ███ was also-- through her treatment she would be quite sick and have a lot of upset belly but it was only when she was on treatment or on antibiotics and, basically, any time you had the slightest bit of diarrhoea, you were in isolation. Your room was locked down, you had to be 48 hours clear.

I had to kind of fight with infection control and say to my consultant that I wasn't happy because ███ was only being locked into lockdown because of the treatment and because of the medication that they were prescribing her. It was all side effects. So, we were isolated constantly because, through the treatment plan, that's what the side effects are. So, the fact that they knew this, and they still isolated us knowing it wasn't an infection our kids had, it was just part of treatment but for them, it was easier just to isolate us to a room.

Q Did they say whether it was because they were concerned that ███'s diarrhoea might pose a risk to others on the ward, is that it?

A Basically, they says it could have been an infection and it could be passed on and stuff. But until she started her chemo or started an antibiotic or getting certain medications which brought it on, and over time you've seen a pattern. Infection control were constantly putting you in lockdown, and the ward would say, "Oh, it's not us. It's infection control." And basically, I ended up having to say to my consultant, "I'm not happy with this because we were never out our room." We were locked in our room constantly, or you would get out for a day, and then they would give her an antibiotic or give her chemo, and that would be it away again, and that's you locked in a room again.

Q I mean, you say out for a day, at this stage "out for a day" would mean just out into the rest of the ward?

A Just up and down the wards. Being able to put her in her pram and take her over to the other building, just for a walk. I wasn't allowed off the hospital grounds because ███'s treatment was quite intense in the first few months, so we weren't allowed to leave the hospital. We were always within the hospital.

So, she was used to getting up in the morning and we'd go over to the canteen, and we would get her a wee roll and sausage or whatever. The morning, it was toast or cereal every day. And obviously, when you're at home, you've got a selection of food.

So, when we were able to take her for walks and stuff like that and get her rolls and things like that, it made her-- it just broke up her day a wee bit from being stuck within this ward.

Q And when you're describing being able to go, to leave the room on those occasions and go elsewhere, was that still just within the children's hospital?

A No, we were allowed to go through the tunnel which took us into the adult hospital so we could go to the canteen because in the children's hospital there wasn't anything like shops and things that were within the adult hospital. The only thing that was in our hospital was a coffee shop, which is obviously-- that's no good to a two-year-old child. Whereas if we went over to the adult building, the canteen, we had Marks & Spencers, we had WH Smiths, we had the soup bar. We were able to give her more of a choice to pick stuff that she actually wanted instead of stuff that was given to her on a daily basis because that's all we were getting served on the wards.

Q How often was it that she was allowed out into the ward and out into the rest of the hospital?

A Very rarely. Very rarely in the first few months because we were in isolation most of the time because, as I say, her treatment was giving her sickness and diarrhoea, and basically as soon as you have that, you're isolated. Infection control isolate you straightaway.

Q And do we understand from your evidence – it's paragraph 32 for those who want the reference – that there would be times when you would see a sign or some tape go up on the door, is that right?

A Yes, that's correct. We would always have a sign put on the door, "This room's in isolation. Do not enter unless you basically were prepped with like aprons and gloves," and stuff like that because-- The side effects of treatment is a normal thing, you would think that they would already be set up. Like, they should know that's part of treatment, but they were having to come in with gloves and aprons and stuff like that. Obviously, they were going to other rooms with other children, but we were always getting signs put on the door.

Some days you wouldn't even know you were in isolation. You'd wake up in the morning, you would open your blinds and there would be a sign on the door, and ███ would get upset and go, "Mummy, I've got a sign. That means I can't go out." Like, she

knew when that yellow sign was on the door that she was in that room, she wasn't allowed out it, and for a child to understand that at two, it's not a very nice thing.

Q Yes, and she turned three, I think, over the summer of 2017, is that correct?

A Yes, that's correct. Yes.

Q And that would be during the period that all of this was going on, is that right?

A Yes.

Q And what was the effect on ███ when you think about those months of predominantly being locked down into your room?

A It was just-- You'd see her kind of deflated. Her wee happy self wasn't there because she wasn't allowed to go and play with anybody, she wasn't allowed to mix with anybody. Like, it just-- it wasn't the way a child should be living. It was not fair. Like, we were-- Towards the end, we started getting a few hours at home, to the stage where if we could go home, she didn't want to go back to the hospital because she was allowed to play with her brothers and see her dogs and stuff like that. So going back in there and going straight into an isolation room, she didn't like it at all.

Q I think you say at paragraph 35 of your statement, Ms Cunningham:

> "The hospital was her life. She didn't know about running about with kids, she didn't know her ABCs, she knew nothing other than the hospital."

Is that right?

A Yes, like she could tell you names, she could tell you when she needed certain medication. Like, when she was turning three, she could tell you that-- I'd say, "Do you want me to buzz for paracetamol?" and she'd go, "No, Mummy, I'm really sore." Like, she could tell you when she needed morphine, she could tell you when she needed her cyclizine, her anti-sickness. She didn't know her ABCs or her colours or stuff, but she could tell you her treatment, like what she needed. She knew when she needed anti-sickness, she knew when she was itchy for Piriton, she knew when she needed pain relief. She could tell me what she needed, and she didn't know normal children stuff but she knew medical term stuff.

Q If we just move through the timeline a bit then, Ms Cunningham, I think we can see from that that round about August/September 2017 ███ had completed her rounds of COJEC by

that time, is that right?

A Yes, that's correct.

Q And I think, as you've just indicated, mainly she was in the hospital for all of that, mainly she was in her room for all of that, but did you indicate that there was some time where she got out the hospital for a few hours? Is that right?

A Yes, we were allowed to come home for a couple of hours. We would get to come home; we'd leave late in the morning. We would just need to check her bloods, wait on her results to come back to make sure, obviously, she wasn't neutropenic. And we would get to come home for a few hours throughout the day, but obviously we had to be back in for certain times and stuff like that for medications and stuff. So she started getting to come home and have a bit of fun, but it was only for a small period of time because when she was rescanned at that time, we'd seen that the tumour hadn't shrunk enough for surgery, which took us back into the ward to give her a few rounds of the CVD(?) chemotherapy and basically that was the highest chemotherapy. It just broke her body down, like completely destroyed anything she had because it was that strong, so that we ended up in a ward in a room

where she was in that much pain, she was that neutropenic, that they had her on a morphine pump.

███ had a high pain threshold, so basically the pain team had said to the nurses, "When you go in with with morphine, you need to start higher and work your way down." They never. They started off slow. This was a weekend and there wasn't any-- Through the weekend, you didn't have any of your pain team on, it was just an anaesthetic doctor, and basically started her off, and I kept saying to them, "That's not strong enough." I was having to push the button for the extra morphine, and they were saying to me, "Oh, it's too much," and they added in ketamine to her pain relief at this point, and ███ was basically awake for about 32 hours. She was hallucinating, she was panicking, she was seeing people in the room that weren't there and it was all because of the ketamine. She'd took a bad reaction to the ketamine. Like, she had a fan in her room 'cause she had a temperature so her pillows-- she kept telling us her pillow was really warm and I'm having to put her pillow over at the fan and then give her it back, and it was like every two minutes she wanted it fanned down to put it back on her.

She would see my mum in the room, she was seeing her brothers in the room and then shouting for them and it wasn't. It was just the ketamine had started her hallucinating really, really bad, and she was awake for like 32 hours solid.

As soon as the pain team came in on the Monday morning, they were really, really angry. They were like, "They should have never went in with the ketamine." If they'd looked at her record properly, they would've seen that the pain team said that she needs to start on a higher dose of morphine and get released down, but they never. They just brought in ketamine, and it just really didn't agree with her. She was just in a terrible, terrible state. It was horrifying to actually watch it.

Q I think by this stage in September [redacted] was ready to go to surgery, is that right?

A Yes, that's correct.

Q But you were given a bit of wee break before that, is that right?

A Yes, we were given-- Basically, before she went for her surgery, they had to take her stem cells. So they done that, and we got a wee break to Craig Tara. So we went there but we were meant to be there for like five days, but after three days they had phoned and said that they didn't have enough stem cells for [redacted]'s transplant 'cause obviously [redacted] got the same stem cells back. It wasn't a stem cell donor. Her stem cells were basically pumped through a machine, they were cleaned and given back into her. So we had to come back from the holiday after three days, back to the ward to do that and then basically we were moved up to Ward 3A which was basically where went to go for her surgery.

Q Did you say 3C there?

A 3A.

Q 3A. And how was after her surgery?

A Her surgery itself was quite a long procedure. She was in surgery for 10 and a half hours so being at home away from the hospital, and basically they said they would phone to give us an update and I didn't get an update until near enough 8 o'clock at night. They'd phoned to say that surgery was a success; they'd removed 90 to 95 per cent of her tumour, and that was them just basically closing up her abdomen and for myself and her dad to make our way up to the High Dependency Unit, the Intensive Care Unit. And we got there. [redacted] basically had a full sad face right round her whole belly, like there was a scar right round.

So we were kept in High Dependency for-- We were quite lucky. ███ was due to-- Basically, she should've been in an induced sleep for like 40 hours, but she woke straight up and asked for Irn Bru and nippy crisps. The surgical team were kind of quite shocked. So, basically, obviously she still had her epidural in her back, she was-- lots of wires were in everywhere so we had to go to the ICU, but ███ was quite lucky that after the next day she seemed to be all right that they could take some of her stuff away, and after-- On the second day, checked her kidneys and her bladder to make sure everything was in working order, and we were then moved back up to the ward. So

███ kind of bounced back. From everything she went through, she bounced back really quick. So within like 10 days we were back home after her surgery, which shocked the nurses and doctors because they were quite shocked, like kids don't usually bounce back as quick and ███ was up and walking about on the third day and wanting to go to the playroom and things like that.

Q And are you indicating that over that spell, prior to her bouncing back, she did go into the Paediatric Intensive Care Unit? Is that right?

A Yes, ███ was taken straight to-- She was taken straight there from theatre, so basically that's where I had to go and meet her. Obviously when you're in there, you're not meant to be allowed to stay there with your child overnight. You're allowed to sit there, but if you've got (inaudible), you're meant to leave. But, as I say, ███ was that attached to me she wouldn't really sleep with anyone else. So even if I got up to go to the sink or the bin, you know, the toilet, she was jumping up, like trying to pull herself up. And it got to the stage where the nurses said, "Listen, we're not meant to do this but ███'s gonna be more at a risk of bursting her stitches or hurting herself if I wasn't beside her." So they brought me in a recliner chair and gave me a cover just to kind of be at the side of ███'s bed because ███ wouldn't go with anyone else. She was attached to me since she was born, so me not being in her sight was going to cause her more distress that the nurses asked me to just stay with her so she didn't get upset or pull any of her wires out or anything.

Q And it was after that that she bounced back, is that right?

A Yes, that's correct. We

moved back up to the ward on the second day. Obviously, she still had a catheter in, she still had her epidural and stuff like that, but when we were on the ward she started-- On the third day, they took the catheter out, took the epidural out. They did still have her on a morphine pump at that point, just to try and keep on top of the pain, but she was up and she was standing. She was taking short walks. Her room wasn't too far from the playroom, so she was managing a wee 10/15 minutes out of bed and into the playroom, and then she would get a bit tired and go back. But she did, she just bounced back from it. I was in shock, the doctors and nurses were in shock that we were home within 10 days. She just took it in her stride, so she did.

Q Now, can you walk us through the next stage? I think that's stem cell surgery.

A That was the stem cell transplant. So basically that was in September, so my birthday was ███ and we were still on the ward, and that day basically they gave █ the highest dose of chemotherapy that she could get which basically broke her body down to nothing. Like, she had to have no goodness within in her body (inaudible – background noise). So they done that.

The next day, we were moved through to the first room when she came into the ward, one of the transplant rooms. When we were in there, that's where transplant-- stem cell transplant was carried out. That was one of the harder parts of treatment because you're not allowed visitors. We were rarely even allowed out of the room, like nobody can come in the room. If they come in, it's double doored. So basically when I was coming in, I would have to take off outdoor shoes and stuff to go into the room with her. But that was one of the harder parts of treatments because there was days where she was lying in the bed, but her nose was just constantly pouring blood, so she was-- ice packs and platelets running constantly, like that was one of the hard parts. She was breaking out in rashes from head to toe, big red blotches all over her. Like that's one of the worser (sic) parts of treatment that I did see her go through. It was horrific to have to be stuck in a room and watch when no one can basically help you, or go out the room to the parent room and have a cry because you had to try and keep yourself away from any sort of bacteria or infection,

anything, so you weren't really allowed anywhere. You were only allowed one person like myself, and her dad in the room.

They did make a certain-- They did allow my mum to be a third person. So if I wasn't within the room, my mum was allowed in but that was only so I was allowed out to see the boys because obviously I wasn't able to see them. And the transplant was quite a long period, so not being able to see your other two children was quite hard, so they'd given me an exception that my mum could sit with her within the room. But basically, I was only allowed out to stay with the kids for not long and then I had to come back in another room. I'd need to take my outdoor clothes off, change into different clothes before I came back into the transplant room.

Q And you set all of that out at paragraphs 47 and 48 of your statement, and really, in summary, I think what you're saying is that

█ was severely unwell after this process and she was even more isolated than she had been before, is that right?

A Yes, that's correct.

Q But are we right in understanding that the stem cell transplant was a success, and she was discharged in October?

A Yes, basically they said the stem cells had been a success. We were told that there was no certainty that some of the cells might not have been cleaned and stuff properly because she got her own stem cells back, but obviously neuroblastoma could've went back into her because not every stem cell could've been properly cleaned before going back into her. It was basically a (inaudible), and we were discharged in October, and then we went back in in the November for scans and basically at that point we had seen that the neuroblastoma had reoccurred.

Q Yes, and I'll come onto that in a minute. She's discharged in October, and I think implicit in what you've just said is that she goes on to outpatient care at that point, is that right?

A Yes, that's correct.

Q Now, I want to look at events in November. I'm going to ask you about two things. You've already mentioned one of them which is the recurrence of the neuroblastoma – that's the second thing I'm going to ask you about. The first thing I'm going to ask you about is an infection. Are we right in understanding that on about 22 November you had to take ███ to the

hospital with a fever?

A Yes. Basically, you get to the stage where you're-- Obviously, a normal fever for a child is 37.5, you'd give Calpol, but we're not allowed to do that. As soon as we reach 38, our kids are admitted straight to the ward for antibiotics. And basically, they used ███'s central line and then they put antibiotics in and then they flush it through with fluids, so we left the wee room we were in, went out to the play bit. And just after, very, very fast, was just pure kind of shaking, and I was like, "What's going on?", and I said to the nurse, "███'s shaking, like she's not looking herself. She's quite jerky." So the nurse said, "Let's go back in the room."

We went into the room, and it just got worse and worse and we checked ███'s temperature and it showed that her temperature had (inaudible), as in very high. They were trying to flush fluids through her, like pump-- like they were flushing fluids through, they tried ice cold fluids through her and she went into a wee-- the cold had triggered seizure. She was in this for maybe about 45 minutes. After about 10 minutes of the nurses trying, they told me that they had to phone for the crash team and stuff they wanted up really, really quick because ███'s

seizure was getting quite out of hand, her temperature kept rising, her seizure was getting worse. So basically they had phoned them to come up. She said, "Listen, the room's gonna get really, really full. Just hold the oxygen mask to ███'s face and try and not look up." I had an oxygen mask at ███'s face, the alarms were going off and at that point the room became full of doctors. And I remember I did look up at one point and the doctors were just going into veins and ███ basically with ice cold water because her temperature was that high that if they didn't get her temperature down it could basically cause quite a bit of damage to ███'s brain. So with the team working on her, it took them about 45 minutes to stabilise ███ at that point.

Q And did they eventually get her stabilised?

A We did manage to get her stabilised, the seizure to stop, and still had to keep the oxygen on. Once that team had basically finished, a doctor had come in to take her over and stuff, but at this point she was just very-- she was totally exhausted, she was totally drained by the stage this happened. The temperature had come down a wee bit so once we managed to stabilise her within Ward

2B, we were then readmitted into Ward 2A, which was obviously the normal ward.

Q And are we right in understanding that about a week after that she had her line removed?

A Yes, that's correct. had her line removed because they found another infection again. But, at this point, this was ███'s eighth line that she was having inserted.

Q So the new line would be her eighth line?

A Yes.

Q And at this time were you given any explanation for what had happened?

A No. They just said that there was an infection, they tried to treat it with antibiotics basically to get the infection out the line and if the antibiotics didn't work, they'd tried and flush the line. Nothing was working, so they had no option but to basically take the line out again. Obviously, was due scans at this point as well and it was just shortly after that that we found out she'd relapsed. And I'd asked on numerous occasions for a port to be inserted, which would be under the skin, so there was no chance of being able to catch infections 'cause it's within the body. But because ███'s chemotherapy and

her treatments, they really needed the Hickman line. So there were two lines and they attached an extra line so she could have three or four things going in and out at the one time because mostly her treatment was that needed(?) so we were denied a port, like we weren't allowed. We were told the port wouldn't be enough for ███'s treatment.

Q Thank you. Now, I'm going to go on in a minute and just ask you about ███'s relapse. But just to complete what you've said on the infection and just to understand what you were told, are we right in understanding that you were told that it was an infection?

A Yes, we were told there was some form of infection within the line which meant it had to be removed.

Q But you weren't told what it was or how it had happened, is that right?

A No, they just said it was an infection.

Q As you say, Ms Cunningham, there were two things happening now and one of them was that unfortunately the scans showed that ███ had relapsed, is that right?

A Yes, that's correct.

Q And you set this out at the beginning at paragraph 64, for

those who wish for the references, that you were told that in fact the cancer had reached ███'s brain, is that right?

A Yes, that's right.

Q And there was a discussion about options, and are we right in understanding that you decided that the best thing was that ███ go onto palliative care at that point?

A No. That wasn't at that point, no. Basically, there was only one option of a drug called the Beacon trial, but there were only two rounds of that. So we did go ahead with one round of it and basically it made really unwell, and she was quite lifeless, she was being sick, she wasn't well with it at all. We were then taken and spoke to a doctor about it and they said, "Well, this is your option. You can either go ahead and try the second one, but the scan has shown now that it's spreading through her spine, in her back, through all her body." So basically we said "No. We're gonna just leave it". But at this point my doctor hadn't told me that that was basically it, that ███ was going to-- that was her.

We were sitting in Ward 2B and I remember walking out the corridor and one of the nurses came up to me and she gave me a cuddle and she was crying. She was like, "I'm so sorry,"

and I was like, "What are you talking about?" And then I'd went in, and I spoke to one of the Outreach nurses in 2B and I said, "Listen, what's going on here?" But at this point they'd moved me up to neurology because basically it was the brain, and ███'s consultant and one of the Outreach nurses came up to the ward and basically the Outreach nurse said, "You need to explain what's going on here," and basically, he said that there wasn't any more options, like that was it. So the nurses and things that knew that didn't have any other options, that was gonna be us at that point.

When I was in the neurological ward, they did say that they could put a stent into ███'s head 'cause the pressure was causing her pain. She was on lots of pain relief, she was on steroids to try and release the pressure. But basically the doctor said to me that, in his personal and professional opinion, he wouldn't want to put her in a stent because, one, she would probably not make it off the table, and two, it could've caused meningitis in the brain if they did do that.

So at that point we were discharged from neurology, there was nothing more they could do, and we moved home. But at that point we

were just home and then ███, on 1 January, wasn't well or she wasn't eating, wasn't drinking, her stomach was really swollen, and I'd basically phoned the hospital. We were taken in; they first thought that she needed a bit of gut rest. They thought she had a gut infection, so they inserted the tube up her nose and into her stomach and there wasn't a lot coming out into the bag whereas if there was an infection in her gut, this would have sucked into the bag.

And basically it took them a day and a half to go, "This isn't right," and we ended up going down for a scan to be done of her stomach and it turned out that the cancer had spread through her spine and took over her bladder and her bladder had actually stopped working at this point, and I was told that she had to go to theatre to get a catheter fitted. The catheter was fitted in theatre, and they got like a litre and a half of fluid out of ███'s bladder. That's what had caused the swelling. That her belly was that risen and that shiny – there was that much fluid in her bladder – her bladder could've burst. So at that point I was told that she'd have a catheter in now until the end, that her bladder had stopped working because of the cancer.

Q Now, you've told us in

your statement that ███ passed away on ███, is that right?

A Yes.

Q And we can also see from your statement that you have some concerns about aspects of ███'s care in her final days.

A Yes.

Q If you're able to, do you want to tell us a bit about that?

A Basically, we were admitted to the ward on the 1st, and on 5 January, her consultant wasn't on, so I'd seen a different consultant who worked alone(?) with ███, and basically I was taken into a room and they basically said, "Listen, there's no more options. We're gonna start palliative care." And at that point I had to sign a DNR order because I knew ███'s cancer wasn't going to disappear. I knew that was it, but I did sign the consent and I said I didn't want her resuscitated. I didn't want her to be ventilated. If we were out and about-- I wanted her to be able to go back home. ███ didn't want anywhere apart from home.

So we had come home at that point, but I did sign on it saying that if there was any sign of infection, ███ could've been treated with antibiotics. So on the 5th we were basically-- the nurses came in, they

put pumps into her legs and stuff. They had her anti-sickness, her pain relief, steroids, everything was getting put through these pumps into her body. Obviously at home I'd set up her tube, like she had her feeding tubes. I had that going and she had the fluids going in, and she was fine for the first few days. We were discharged on the 5th. She was fine, we were out and about, I took her to McDonald's, she was eating, she was drinking.

And then on the 8th of January, I said to the Outreach nurse, "███"-- She was showing signs of the way she went when she had an infection within the ward. And basically the Outreach nurse said to me, "Well, we can't do bloods," which I knew we weren't allowed to do bloods, but obviously at that stage in time we were discharged and told that ███ had weeks into months to go home and make memories. Like, we had came to the conclusion that we had weeks to months. That's what the doctor's opinion was, and on 8 January I said to the Outreach team, "███'s signed off." "Won't do bloods." I said, "No, I know that" but obviously my head wasn't thinking properly. But a doctor and a nurse sat down with me to do her DNR order and it states on it that

antibiotics can be administered to if she was to show signs of an infection, which she was, but they didn't offer it.

And then ███ just kept deteriorating and getting sick and she had diarrhoea. She wasn't well at all, and obviously we had phoned the Outreach nurse and said, "Listen, she's really unwell," and they said to me, "It's probably the pressure on her brain that's causing stress," and they told me to give her midazolam, which I had in a locked box in the house. First of all, they told me to give her 1ml, like a 1ml syringe, so I did. But it turned out it should have been a 0.1ml that I was to give ███. So basically that just put ███ into a sleep, but she was showing every sign of an infection, so the fact that we were discharged and told to go and make memories and we only got █████ at home was quite a shock. And the fact that they didn't give her antibiotics when it's in her DNR order that they could've been administered-- I knew they wouldn't take bloods, but they didn't even offer. Knowing where my head would've been, the Outreach team or the doctors didn't offer to give ███ the antibiotics that could've prevented her passing away as fast. Like, I'm not saying this infection wouldn't have-- I

knew ███ was going to pass away, but we were told that she had longer, and the fact that when I stated the signs of the infection and it was just basically discarded. That's what hurts because I feel as though that could've took time away that we could've made memories.

Q Thank you. Ms Cunningham, I want to go now and have you maybe just describe your main concerns about ███'s care. I'm just going to take you through those in order. The first is the one I think you've just mentioned: as you've indicated, you had signed a form, a Children/Young People Acute Deterioration Management Form – I think probably what we would all understand to be a DNR form, is that right?

A Correct.

Q And, as you've just said, that indicated on it the forms of intervention that you would agree to and that you wouldn't agree to if deteriorated, is that right?

A Yes, that's correct.

Q And one of the ones that you said that you would agree to is that antibiotics could be considered to manage any fever, is that right?

A Yes, that's correct.

Q I think in your statement you indicate that the DNR form and some other information is not actually included in ███'s notes, is that right?

A Yes. Basically, when I spoke to my solicitor, like, the date from 1 to 5 January, where we're in the ward, and they were discharging (?), my solicitor had to ask me why she was in then, because there wasn't any notes in her case notes, and there seemed to be a lot of her notes--consultants and things that were missing. I had to explain why we were in the hospital from the 1st to the 5th, and that was quite an important time because she went into surgery for catheter. They were discharging palliative care but they knew she was in the hospital and she was discharged, but they didn't know why – I had to explain why that was.

Q Thank you. Now, a second issue that I think you have a concern about and that you've touched on today is about cleanliness on Ward 2A. More particularly, are we to understand that your concern is about the amount of cleaning that you saw going on?

A Yes. Yes. There was constant cleaning. Like, it started off you would get your cleaner in the morning, somebody would come in at night just to change the bins. But at

this point, it got to the stage where there was cleaners coming in two or three times a day, the wards were constantly being cleaned, and there was a substantial amount of cleaners being brought into the wards, rooms being completely shut off with like tape; there was big plastic coverings around the door. And basically, sometimes you walk by, and the blind was open, and they had vents pulled down and there was a really strong smell. So, it wasn't just normal cleaning materials that they would use, it was like industrial cleaner. It was very, very strong smelling. If you were walking up and down the wards, you couldn't miss the smell of it.

And, as I say, obviously, used to just get a cleaner in in the morning, your bins changed at night, but they were coming in a few times a day and it got to the stage everything was getting cleaned; it wasn't just the floors, the toilets – they were cleaning all around the bed, pulling things out, cleaning absolutely everything in the room. And as I stated before, that's why everything had to be sent home because we weren't allowed anything lying about anywhere in the toilet area within the ward, within your room area. The floor had to be cleared at all times.

Q Now, when you mentioned a moment ago there about industrial cleaning, you mention this in your statement, it's at paragraph 78 for those who wish the reference, and you indicate that that was something you noticed in November or December 2017----

A Yes.

Q -- and that takes me back to something I asked you about earlier: are we right in understanding that, as far as you can recall, you actually saw an increase in the amount of cleaning over time?

A Yes. The first month or two, we were absolutely fine. It was like the happiest place to be for your child. And then, after a few months, maybe two/two and a half months, everything became very, very strict. It wasn't like a children's ward; it was like being somewhere as if the children had done something wrong. They weren't allowed to have their own things. It just wasn't a nice place to be. Like, ███ was used to this happy wee place, and then we didn't understand why her stuff was going away, why she wasn't allowed to do certain things that she had been doing. And explain that to a two-year-old-- you can't explain it. It's taking(?) everything from them, and the happiness that they had for the first

couple of months just disappeared. It wasn't a nice place to be for a child.

Q And just speaking about not being able to explain it, are we right in understanding-- If we move on to a third concern that you've got, are we right in understanding that, about three years later, you watched a documentary on the BBC about the hospital, is that right?

A Basically, I had never heard nothing at all, I was not knowing anything. I did know, in December 2019, that stuff had came out about the water infection – but to me, ███ had passed away, I didn't give a second thought. One newspaper had contacted me to say do I have anything to say on it, did I want to speak about it, and I'd said, "Well, no because ███--" to me, I didn't know anything about it, so that wasn't a concern of mine.

But obviously, on 4 March 2020, I received a letter, which I've sent to my solicitor basically saying that – from the Scottish government – ███'s case is going to be reopened because they thought she was one of the kids infected with the water infection. And that kind of took me back, because that's like two and half years after my daughter died, and to get hit with that was really distressing. Basically, that

was in March.

We were then sent a big, huge booklet, which is in April, which broke down things. But obviously, when you're not a professional nurse, doctor, or infection control, you don't know what's percentage-- that there's 17 percent of this, and you don't understand it. And then, obviously, there was a documentary just after it, and it made you really upset and angry because it stated that they knew about the infection before the hospital was opened, it was addressed for two years without anybody doing anything about it. Basically, the woman that done the documentary, she went away abroad, and eight people said they would've never opened the hospital.

At that point we found out that one of the antibiotics that our kids were on which was making them unwell with really, really bad diarrhoea and stuff. We were told it was part of protocol, but it wasn't. That's when we found out the antibiotic was particularly to treat bacterial infection that comes from water, which made me question, "Is that why ███ had so many line infections because she was always in the baths? Could it prevent the chemo from doing its full effect if the line was always infected?" Also quite hard because we weren't aware of it, but if I

knew there was anything going on like that when ███ passed away, I would have asked for a post-mortem to be done. But obviously we were neglected of any information and, obviously, for the like, two and half years I was out the ward, obviously other people knew what was going on as they were moved over to Ward 6A and Ward 4A. I wasn't within that ward so, basically, I wasn't informed about nothing.

Not one thing was I told about until the Scottish Government contacted me, and that's when I started doing investigations. And I'd contacted the ward to say, "I had this letter, could I get Jeane Freeman's number to speak to her about it?" And the nurses were, "Oh, that's--" they never ever knew anything like that. And don't get me wrong, the nurses' care was fantastic. I can't fault-- had a great bond a few of them, but it's the way the made out as if they never knew, but they did because they were ones that were administrating these antibiotics to our children. But the doctors and nurses and all the infection control, they knew. That's why it all made sense when this all came out, what started happening. But the thing is, because ███ had died, it was as if they didn't want to--

need to inform me.

And then, obviously, the Scottish Government came to me to tell me about it and I was angry, I was upset. You don't get over your daughter passing away, but if this infection was what was in her line towards the end and it's took her sooner, if it's prevented her treatment from working properly-- I have so many questions that I need answers to. We've been neglected a lot; if I knew there was anything going on, the first thing I would have done when ███ passed away would be ask for a post-mortem, but I wasn't given that option because the hospital staff and the medical staff and the infection control, they didn't give us a chance to know anything was going on.

Q Thank you. So, just to try and summarise some of that, Ms Cunningham, and I'm doing that because you did break up a little bit there, I think we've got 90 percent of what you said, perhaps more than that. I'm just going to ask you to summarise it or----

A Yes.

Q -- summarise my understanding of what you've said. You got a contact in March 2020, I think, out of the blue----

A Yes.

Q -- that ███'s case was being opened up, is that right? And I'm going to ask you some more questions about that. Is that right?

A Yes.

Q Yes. And then there was some more correspondence, and then eventually you see the BBC programme, and I think a number of concerns for you emerged from that.

A Yes.

Q One of them, I think, is that it was your understanding from that programme that the Health Board had known about an issue with the water supply for some time and had done nothing about it. Is that right?

A Yes, basically they knew about it before the hospital opened. They knew about it for a further two years, and there was a woman who came forward as a whistleblower and said, "Listen, I've been told (inaudible) about this over and over." And she was told "Don't write anything down. We just talk about it verbally." And eventually the woman went, "No, this can't be right." And it was her that basically whistleblowed that made them look. So, basically, what was getting addressed about the water infection was getting put to the bottom of (inaudible) two years once the hospital opened.

Q And the second thing was, of course, you understood that had had an infection while she was in----

A Yes.

Q -- the hospital. And that leads to the third thing: did you start to wonder whether there might be a connection between the issue with the water and ███'s infection?

A Yes. Basically, through ███'s 10 months of treatment, we never got a lot of time at home. So, basically at home, ███, if she was in a bath in the house, we had to wrap it up; she wasn't allowed to go swimming; she wasn't allowed in paddling pools; she wasn't allowed to do nothing. The only place ███ was really within the water was in the hospital; she would have a bath the way she would have it at home, with her bath and her jammies and stuff like that for bed. And it just made me wonder. She had eight central lines in 10 months which is a substantial amount of lines when, usually, a normal case, you only go through two to three in a year period of treatment. And obviously, the fact that ███ had eight is starting to make me wonder, "Is this what all these infections had been? Had infection in the line? Because it's in the main artery it

prevented her chemotherapy from doing its full effect? Is that what led to her relapse?" Because basically her transplant was all through the central line as well.

So, questions started to pop up my head of "whats", "ifs", and "buts". I'm not saying for one second my daughter would not have passed away because her body at the end was riddled with cancer, but I think that them not giving her the antibiotics when I asked, I think that prevented the time we had. And also, as I said, questions are in my head now of all these infections she had and having to go through surgery. It wasn't one surgery; the surgery to remove the line and then, 48 hours later, she'd another surgery to reinsert it. ███ had scars in all different parts of her neck where lines have to be inserted. So, if this infection was going into the main artery of her body from these lines, what damage did that cause? And again, has that prevented ███'s treatment from doing its full effect?

Q Thank you very much. That takes me, really, to the fourth concern that I understand you to emphasise in your statement, and that is about ███'s infections, and I'm going to ask you some questions about that. Before I do that, Ms

Cunningham, we've been going now for about an hour and a half. I suspect it will take us about half an hour to complete your evidence. Would you like to keep going, or would you like a brief break?

A Could I have a brief break if possible?

Q Of course.

THE CHAIR: Certainly. Will we say 10 minutes?

THE WITNESS: Yes, that's fine.

(A short break)

THE CHAIR: Ms Cunningham, I can see you. Can you see us?

THE WITNESS: Yes.

THE CHAIR: And clearly you can hear us.

THE WITNESS: Yes.

THE CHAIR: What I should have said that at the beginning is that, because of the camera position, it may seem that I'm looking over your shoulder. I mean, I don't know if you're seeing shots of me or not, but it may seem to you that I'm somehow distracted by looking left and right. The reason it looks that way is that I'm actually looking face on at the screen at which you appear. But it occurs to me that it might look a little bit impolite, as if I'm not paying attention. What I'm

actually doing is trying to pay full attention. Now----

THE WITNESS: Yes.

THE CHAIR: -- Mr Duncan.

MR DUNCAN: Thank you, my Lord. Ms Cunningham, I was just going to move on, really, to ask you about one further matter, and as I indicated earlier, it's your concern around infection. And you've already told us quite a bit about that, and that ███ had a number of infections, as you understand it, and had to have her line changed on eight occasions, is that right?

A Yes. She had eight lines all in.

Q Eight lines all in. And I think you've indicated that you got this out of the blue communication that ██'s case was being looked into in March 2020. You've then got the BBC programme, and I think you indicated that you yourself started doing some further investigations.

A Yes, that's correct.

Q I think about a year after March 2020, so about a year after, you were told that ███'s case is being looked into. You did actually receive the report from the Case Note Review, is that right?

A Yes, that's correct.

Q And I think that we understand there to be a large, detailed, and complex general report and then an individual report. Is that right?

A Yes, that's correct.

Q Now, I think it's obvious from everything you've said today about this and also what you say in your statement that you have quite a number of concerns about the whole way that that process was communicated. Is that right?

A Yes, that's correct.

Q Yes. As to the actual conclusions of the Case Note Review in ███'s case, I think you set them out paragraph 92 of your statement. Is that right?

A Yes----

Q You summarise them.

A Yes, I think so, yes.

Q Maybe just turn that up because I think we'll just walk through this.

A 82, sorry?

Q Paragraph 92. And I think if I was just to summarise what I understand them to have said, I think it's this: that ███, as we know, she was discharged, I think, on about 26 October 2017, and she's a day case attendant after that, is that right?

A Yes.

Q Yes. And sorry, having

asked you to look at paragraph 92, not everything that I'm saying is in that, so I apologise.

A No, no. I know.

Q We know that she came to hospital with a fever on 22 November. That's right, yes?

A That's correct.

Q Yes. And one of the things I think they say is – and you've more or less indicated that today – her line was flushed, and her condition deteriorated after that, is that right?

A Yes, very rapidly, yes.

Q And in fact, the way they describe it, I think, is that actually caused what they describe as "a collapse". Is that right?

A Yes.

Q And the crash team had to be there.

A Crash team had to be called up. Yes, they couldn't get on top of it themselves. Within a couple minutes that they had to put out a code, and I was just told that the room was going to get really busy, and not focus on what was going on in the room and just focus on ███.

Q Yes, and as far as an explanation for all of that, I think what they say is that there were cultures taken at the time, and these----

A Yes.

Q -- show infection from two types of bacteria, is that right?

A Yes, that's right. Yes.

Q And those were something called enterobacter cloacae, is that right?

A That's right.

Q And another one which I find quite difficult to pronounce, but I think it's raoutella plantilcola or something like that----

A Yes.

Q -- is that right?

A Which again we were not-- There was no indication of them telling us exactly what they were.

Q Yes. Now, even in the report that you got in relation to ███'s case, do you think that the conclusions of the Case Note Review people were clearly expressed?

A Not so much, no, because basically it wasn't even put into-- It was a wee bit at the bottom of a page then a wee bit on another page. I knew there was a lot more going on. I was lucky if I got 1000 words from them to indicate exactly what it was. It was hardly any information, any detail, it was just a case of, "Oh, we're sorry. This is what we found." There was no intel to what the infections were. They didn't explain what they were or why she had

two different infections in her line at one time or anything. Like, there wasn't any detailed information. They just basically stated, "This is what happened on this date, this happened when she was in the ward." And then the fact of what they found, and obviously it was distressing the crash team was brought up. Basically put what I knew. There was no explanation to me of anything extra. I only got told what I already knew. They didn't go into detail as much they should have. When all the information came out later on, I realised, you know, that's not even-- Her life is worth more than 1000 words.

Q I've got a couple of questions about that. Just when you say that you already knew, are you indicating to us that, actually, by the time you received ███'s report in April 2021, you already knew about the two bacteria?

A I had heard about them, one of the notes we received. Obviously, I wasn't-- I still to this day don't know exactly what the infections are because I'm not a specialised in that, but obviously I'd read that this is the sort of infection that seemed to be quite common with a few of the patients. They seemed to have the same sort of thing within the lines. But obviously there wasn't a lot of detailed information----

Q Yes.

A -- that I could have got that I would've understood it.

Q Okay. But in terms of those two bacteria being (overspeaking)----

A No, I wasn't aware--

Q -- with ███----

A -- at that point in time what they were, no.

Q And I mean, how did you feel on seeing that?

A It seemed like your daughter's life didn't really matter, that someone who can send you out a paper with a certain amount of words in it is meant to make up for what you went through and what you've then continued to find out. I don't think a bit of paper's the right way to go about it. I know there was lockdown, but there could have been a face-to-face communication – i.e. video link – to go through this personally. But no, they just decided to give you a bit of paper and expect you just to sit and accept it and go, "All right, this is what it was." Yes, but I don't think they went the right about it.

And because I know a few of the parents were invited to meetings, but ███ was passed away. I had

nothing. I seen from the ward page there was meetings and stuff, but never once did any of the parents who had the same thing(?) get invited to any of these meetings to get any updates whatsoever.

Q So, we're now at a stage more than three years after ███ has passed away, and you are reading for the first time that the line infection or that an infection that she had in November 2017 was connected to two bacteria which you'd never been told about before. Is that right?

A Basically, even when she had any of her line infections, we were never really told what they were. We were just told that the antibiotics didn't clear it, and she needed a new line. I got ███'s medical notes - but personally I couldn't go through them, it would've been too hard - which I sent to my solicitor. So again, I don't know what infections ███'s had when we were even in the ward. So, if any of those two had the same one she's had in the past, like, I've not got a clue because I didn't go through anything. The only infection that they stated was the one in November.

Q Thank you. Now, can I have you look at paragraph 92, if you've still got in front of you?

A Yes.

Q And it's just over the halfway point, you say: "The report conclude that they didn't really think…" got that?

A Yes. (Overspeaking)----

Q "The report conclude that they didn't really think that the hospital had anything to do with it." Now, am I right in thinking that those are your words rather than----

A That was my words, yes.

Q -- (overspeaking)?

A From what I got in an explanation on a bit of paper that I think the NHS is trying to say they didn't have anything to do with it. That was my words, but really, at the end of the day, I think it is more information there that wasn't detailed, like in the Case Note Review that I received, or an independent one because it was very plain, very bland. There wasn't any other information. It was basically a few words and then, "Sorry, for your- - sorry if this is stressful(?)". There wasn't enough information for me to say there's more to this because they should've gone into more detail, which they never.

Q I asked you a moment ago whether you thought, even in ███'s case-- I asked you whether you thought that the Case Note Review report was clearly expressed,

and you indicated that it wasn't. Is that right? I think you're indicating to us that the words that I have just read to you, those were your words, your understanding----

A Yes.

Q -- of what you thought the report was saying. Is that right?

A Yes. Yes.

Q Am I right in saying that the report does say that [redacted]'s case-- it does say at one point that there is a possibility that the infection was linked to the hospital environment?

A Yes.

Q Thank you. Ms Cunningham, I have come to the end of the questions I have for you. Have you got anything further that you would like to add before we conclude?

A Not that I can think of at the moment, no. I think everything that I've had in my statement and wanted to put across has been addressed today.

MR DUNCAN: Thank you very much. We have your concluding remarks in your statement, and we will certainly be looking at those. My Lord, I have no further questions for Ms Cunningham.

THE CHAIR: Thank you, Mr Duncan. Thank you very much, Ms Cunningham, and particularly having

persisted with technical problems which----

THE WITNESS: Yes.

THE CHAIR: -- look to have been solved because I've found it very straightforward to follow your evidence. Thank you for providing your evidence directly today, but also-- Actually, what I'm going to try and do is address the camera and see if that actually makes me look as if I'm looking at you because, as I say, I want to underline that, whereas the video feed may indicate that I'm looking away, I have been looking at your image on the screen. So, thank you for your evidence today but also thank you for providing the witness statement, which is, again, part of your evidence. So, thank you very much, and that's the end of the evidence. Thank you.

THE WITNESS: Thank you.

(The witness withdrew)

THE CHAIR: Now, as I understand it, Mr Duncan, that's not only the evidence for today but the evidence for this diet of hearings.

MR DUNCAN: That's correct, my Lord.

THE CHAIR: Right, thank you for your attendance, and I hope that you

have had access to the Practice Direction-- or the Direct Procedural Direction, I think, strictly speaking, number four, which sets out my expectation of how we best use this evidence. As you'll have seen from the direction, a counsel to the inquiry will provide a written closing submission by the 3rd of December. Those core participants who wish to do so are not only free to make their closing submissions but are very much encouraged to do so. You will see that the Procedural Direction itself is short, but in the attached note I've tried to set out some of my thinking as to how we should go forward.

I would strongly commend what appears in the second paragraph of the note; I am looking for your assistance, and I am expecting that you will wish to provide that. And as the next step in dealing with this body of evidence, I would encourage you to respond in the way as I have requested to counsel's submission. I don't anticipate that you will feel confined by that. If counsel has not represented the evidence in the way that you would analyse it, please provide your analysis. And if there are matters which should be looked at further, please highlight them because, as you will see, what I envisage is that,

in relation to the matters which have been covered in five weeks of evidence, there will be more that the inquiry will wish to hear. And therefore, I would find it very helpful if you were to put forward anything additional to what is proposed by counsel to the inquiry for the next stage. It’s a question not just of a further hearing, but the investigative work which is necessary for any hearing.

So, I will be grateful for but equally I look forward to and anticipate your assistance in doing this. And this is a general point, I think the way that we are trying to conduct this inquiry is in a collaborative way. If you have any contributions to make, and I'm sure you've picked up on this, we're very open to hearing from you informally by direct contact with the legal team, and I'm sure counsel to the inquiry will welcome informal conversations or more or less formal communications. We really want to engage with you because I don't think the inquiry will achieve its the purpose of fulfilling the terms in reference if we don't get the assistance of the core participants.

Well, with that, thank you very much again for your attendance. It may be some time before we meet in this particular context but, as I said,

the inquiry will always be very open to being in touch with proposals, comments, and suggestions. Thank you.

13:50

(End of Afternoon Session)