SCOTTISH HOSPITALS INQUIRY

Hearings Commencing
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Day 22
Friday 5 November
Morning Session

CONTENTS

10:00

THE CHAIR: Good morning. Now, Mr Duncan, I think we're able to begin with Mr Behl, is it?

MR DUNCAN: That's correct, my Lord.

THE CHAIR: Thank you. (After a pause) Good morning, Mr Behl.

THE WITNESS: Morning.

THE CHAIR: I think in fact we've met before, albeit remotely.

THE WITNESS: Yes, remote.

THE CHAIR: It's good to see you in person.

THE WITNESS: Same here as well.

THE CHAIR: As you know, you're about to be asked questions by Mr Duncan. I don't know how long your evidence will take. We usually take a break about half past 11 anyway, but if you want to take a break before then, please just give us an indication. We can always take a break. Now, I think you're prepared to take the oath.

THE WITNESS: Yes.

THE CHAIR: Could I ask you, just sitting where you are, to raise your right hand and repeat these words after me?

Mr ABHISHEK BEHL

(Sworn)

Examined by Mr DUNCAN

THE CHAIR: Thank you very much. Mr Duncan?

MR DUNCAN: Thank you, my Lord. Good morning again, Mr Behl. Can I just begin by asking you some formal questions, please? Can you, first of all, confirm that you are Abhishek Behl and that you live with your wife and daughter in [redacted]? Is that correct?

A That's right.

Q And I think your wife is a hospital doctor, is that right?

A That's right. She's right now out of hospital (?) because of-- She's gone part-time since she's also doing a PHD.

Q Yes, and you are a full-time carer for your daughter who, I think, was born in [redacted] 2017 and is presently four years old, is that right?

A That's right.

Q And something I'm going to ask you about later, I think you're also a member of something called the Family Council, is that right?

A That's right.

Q Now, your daughter has a condition known as alternating hemiplegia of childhood, is that right?

A Yes.

Q And is that usually

abbreviated to AHC?

A AHC.

Q Again, I'm going to be asking you a bit about that.

A Yep.

Q And are we correct in understanding that you've provided a detailed witness statement to the Hospital Inquiry in relation to your daughter's condition and her treatment at the Royal Hospital for Sick Children, the old hospital in Edinburgh, is that right?

A That's right, that's right.

Q And you're content that that forms part of your evidence to the Hospital Inquiry, is that right?

A Yes.

Q Now, can I just confirm that you've got a copy of your statement next to you?

A I do.

Q I'm going to begin by asking you a few questions about your daughter and I'm going to take that in steps. The first thing, I'm going to ask you some questions about is the discovery of your daughter's condition. I wonder if we should just maybe start by having you tell us a bit about how your daughter's condition first manifested and indeed when it first manifested.

A Yes, so this all started once-- She was born fine on [redacted], and in about five days' time, she had these fasciculations which are this movement in her thigh, so I found it really fascinating seeing it. I just like watched every type of movement in the leg. But my wife, being a hospital doctor herself, she said that, "Oh no, this looks (inaudible). It needs to be recorded," so we do a lot of recording for the condition. So we recorded many, many times her "episodes", we called it.

Q Mr Behl, can I just have you pause for a moment? I wonder if you could just move the microphone a little bit nearer to you. (Microphone moved) Thanks very much. So I think you told us that you'd seen these tremors and you call them "fasciculations", is that right?

A Yes, yes. That's right.

Q Do you want to continue?

A Yes, so we saw that, and we recorded that and we took her to hospital and that was the first time, five days old, when we actually took [redacted] to the old Sick Kids. But she was admitted for actually having jaundice rather than having that, so that was the start of being an inpatient in Sick Kids.

Q Yes, and I think you indicate that the suspicion at that time was that she may have something called channelopathy, is that right?

A Yes, so that was something which the doctors felt that this could lead to, something called channelopathy, which-- I'm not medical, but yes. It was-- They had that in their mind, but it was not fully seen-- There has to be something related to her condition which we they were not sure of at that point.

Q Yes, and they're not sure of it and they then began a process of genetic testing, is that right?

A Yes, so when she was 10 weeks old, that's when the first episode happened at home where she became totally floppy, and she had her eyes deviated. So we call it nystagmus, so her eyes were all over the place and she had an arched back, so it was like dystonic back that went, and we took her straight to hospital and after that it just became regular admissions into hospital.

Q And those admissions, would those be admissions that involved ambulances?

A Yes, so the first year we had, just roughly, I don't know the number, but I would say 50-plus blue lights into the hospital, was what we thought. Every week, because there were so many medications that she was on, there was no other way to put it rather than through IV. She was getting episodes every week.

Q And are we right in understanding, again just looking at these first weeks and then months – I'm still really just looking at 2017 in fact – that over that period there was a mixture of outpatient and inpatient care at the Sick Kids, is that right?

A Yes, that-- We were not aware of the condition, so it's like you don't know what you have until you get the elephant out of the box type of a thing. You didn't know what her condition is, so it was more like a trial thing that, you know, she was getting these episodes, we were going for MR-- we were going for one MRI she had because she was very young at that point, but she had EEGs, so she had the electric-- electro thing put in just to see if we can catch any seizure-like activities in her.

Q And was it about October 2017 that she had a first seizure?

A Yes, she did. That was when the 10 weeks; one was there. Yes, that's the one.

Q And at some point was there something called an anticipatory care plan put in place for her?

A Yes, so that happened after she was diagnosed, six months old, so she had her genetic testing done in Glasgow where basically we came to know through that she has alternating hemiplegia of childhood. We thought, as parents, alternating hemiplegia of childhood meaning, you know, it'll go off after childhood, but not knowing that it can take paralysis, dystonia, seizures. You know, you've got ataxia, global development delay, epilepsy all in one, so she'll get paralysed left side for an hour, two hours, a week, 15 days. So you really don't know. You know, that's the whole thing of her condition. We are basically living with a so-called "time bomb".

Q And when was it that the diagnosis was eventually identified?

A Yes, so that was when she was six months old. February, is it? February (overspeaking)----

Q Yes, about February 2018, would this be?

A That's right.

Q Maybe just tell us a wee bit about AHC then. Were you just indicating there that in terms of the alternating bit of it----

A Yes, so in very simple terms I say alternating is left or right to the body. So hemi is half, plegia is paralysis, so alternating hemiplegia of childhood, the onset comes when they're in childhood basically. But it carries on to adulthood, so there are people that we know, because I'm a trustee in AHC UK, that we know most of all the kids worldwide, we know their families and stuff because there are hardly any. It's one in a million, the condition, so it's so extremely, extremely rare.

Q Yes. How many children in the UK are affected by it?

A Well, we say-- We don't know the exact amount, but we think it's about 55 to 65, within that.

Q And in Scotland?

A Two. So she's the only one in the east coast and the central belt and there's one in the west coast.

Q And the organisation that you mentioned a moment ago that you are a trustee of is what?

A It's Alternating Hemiplegia of Childhood UK, AHC UK.

Q Now, let's go on then and have you just tell us a little bit more about the condition itself.

A Yes.

Q Did you indicate a moment ago that the impact upon her of the condition essentially varies from time to time?

A Yes, so there's something called triggers, so there are various triggers that actually inflate, like just spark an episode. Things like bright lights or too much of-- I mean, water is a trigger as well because there's so much excitement in water that she gets paralysed, her body, when she's in the bath, and it's happened with us as well. You know, even bright light is a trigger and noise can be a trigger, so lots of things which we don't-- we take it for granted that those can be triggers.

Q So there are various things that can be a stimulus and can trigger a reaction of some kind?

A Yes, yes. That's right.

Q And the reactions can vary, is that right?

A Yes, so depending on-- So she can have dystonia, so she can go fully rigid. It starts normally from her thumb and then within-- We don't actually-- Now we know if you don't actually medicate it quickly, it can actually start spreading, so it spreads to her hand, to her arms and then to her body, and she basically can get quadriplegia, which is four limbs getting floppy as well or stiff, depending on dystonia. Then sometimes, which has happened about-- when she's ended up in ICU, critical care, is when she's actually dystonic on her chest wall which stops her breathing. So that's what we are not wanting.

Q Yes, and that presumably is a blue light trip to hospital?

A Yes, yes.

Q Now, you mentioned a moment ago, or I asked you a moment ago, about the anticipatory care plan.

A Yes.

Q Can you tell us a bit about that?

A Yes, so once we came to know about the condition and we knew that this is something so extremely, extremely rare and the triggers are such that it just varies, there is no so-called pathway like you have for other conditions where you know what you have to do. [redacted]'s care plan is such that you've got everything there, so you've got things like where the carers can actually look into what they need to do at a time of emergency so you can actually-- whoever's with her in hospital or in community it's all there in terms of the pathway of what needs to be done, when you need to give what, what you need to see, what you need to look for, things like her breathing if it's normal or not, and then you follow the path of that. That's all there in the care plan, and as well as it's all connected with the ambulance service as well. So [redacted] has a number which is registered with the ambulance service.

Q So whichever ambulance comes to the house, they know what the situation is going to be?

A They already-- Rather than re-explaining to them about what alternating hemiplegia of childhood is, they already-- They have their first 20 seconds questions that they normally would ask, “Is the patient breathing?”, blah blah, all that, and then they have the care plan in front of them and the -- yes.

Q And in terms of thinking about your role and your wife’s role as [redacted]’s carers, on any given day, how predictable is [redacted]’s condition?

A We get up in the morning not knowing what the day is gonna be, and that’s what I was telling Kenny (?) when we were coming here. I said, “I hope everything goes well for me to be here.” The last three or four days she’s been fully floppy, so she’s had a tough three or four days at home. We try to look after her at home as much as possible because we have everything rather than taking her to hospital. It’s just basically when we need further examinations, then we actually do that.

Q Thinking back to what you said a moment ago about stimulus----

A Yes.

Q What steps do you take at home to prevent any sort of reaction?

A So we have emergency drugs, we have things like various-- So it depends if her thumb starts becoming dystonic, we know what medications to give rather than taking her to hospital at that point. She is on a lot of drugs. We have a medicine bag, a cupboard at home where-- basically all the people who are caring for her, we have the NHS Outreach that look after her as well that take her to nursery 1:1. She goes to a mainstream nursery, so that's where-- So basically we look at medications accordingly to her condition at that point and then we can actually start administering that to her. Then it helps and then we watch, see for 30 minutes or so if it kicks in, what is she doing, how is it changing or what is happening. That's how we take it forward. So every day is different (overspeaking).

Q So to try and think about how you manage it on a day-to-day basis, if we think about, first of all, trying to prevent her from having any episodes at all, you would manage that in part with medication, is that right?

A Yes.

Q But also what about her

environment at home?

A Yes, so that's a good thing that you've brought up. So the environment at home is basically depending on what she's undergoing with her condition. So if she is having an episode-- "Episode" sounds quite nice to the ears, but it actually it's worse than a seizure. So it's basically like she gets floppy, she gets fully paralysed, so we darken the room so it's a dark room that you basically enter and that basically-- and keep it calm. We don't actually-- We're very quiet around her. We don't actually start panicking or-- It's quite funny, in a way, speaking about it, but it actually is quite-- You have to bite your tongue too at that point because it can actually just add to the whole trigger. If you start panicking, it'll become worse, the situation, so yes.

Q So if you, for example, were to see signs of dystonia setting in, as you indicated, maybe in her hands, are there occasions where you are able through the environment and through medication to prevent that going any further?

A Yes. Yes, so she has her regular medications which is given to her from 6 in the morning, then she has some at 8 to 10, to 12, to 2, to 6, to 10, to 12. That's the pattern of our

medications. Adding to that, she has additional "as required" medication, things like the medication that we spoke of. If dystonic, we give her baclofen, a small dose, but baclofen will go as well as trihexyphenidyl, as well as maybe paracetamol at that point if she's in pain. So we give her that and then we have to keep in mind that we've got-- Because we give so many medications, we keep a log, we keep a book. So we are right now on Book 16 or so where basically we keep each and every drug that we've given her, timings, we've seen what she's eaten, how much fluid she's had, and those are all the things which add to her condition.

Q Now, you indicated today and in your statement that in her first year of life, [redacted] had something in the region of 50 or perhaps 50-plus blue light trips to the Sick Kids. Thinking about all the measures that you've just described, can you say whether that has remained the sort of level or have you managed to reduce it?

A We have managed to extremely reduce it, partly because she now has a gastrostomy, so a Mic-Key button stomach, and then we basically give all the medications, and when she's not able to eat through her mouth, her swallow goes – if her left side goes, her swallow goes, so she's not able to chew, she's not able to swallow – that's where we actually feed-- give her everything through the Mic-Key button. So, yes, so it has stopped us going to Sick Kids quite a lot.

Q However, there have continued to be occasions, I think, where things have deteriorated and they can deteriorate quite rapidly, I assume.

A Yes, I mean, it does-- it really varies. We've seen that when she does get-- she's having a bad day, we know there is something. If she's having a good day, we know that we are on borrowed time type of a thing. As parents, we say we are on borrowed time. We know that something big is going to come soon and that's how we see it. We've monitored her daily for years (?).

Q If we think about what you said a moment ago about the dystonic episodes that extend even to the chest area, have there ever been occasions where you have experienced [redacted] having respiratory arrests?

A Yes, we have. She's been in ICU six times in her four years-- in two years, six times, and that's when she was in July, which was the main one when she was in ICU and she got discharged and we came to know that the new place was opening up, so we were basically told, "Don't come here because it's a 24-hour period. If anything else goes wrong, come to the new Sick Kids, not here, because there's going to be no one here."

Q Well, I'm going to ask you a bit about that in a moment, Mr Behl. Before I do that, I've got a couple of other things I want to deal with first. I wonder if you can maybe just tell us a wee bit about [redacted] as a person, despite all of the challenges she obviously faces.

A Yes, so [redacted], she's very, very sociable. That's the one thing which we've basically seen in her from a very young age. We used to take her to a lot of toddler groups, parent/toddler groups, and we used to take her to-- With the condition itself, we used to take her to many-- Even we used nursery at special school with and they were great there, and we saw that she was always wanting to play with other kids and she didn't realise that the other kid is not able to. Because of the kid's medical condition, that kid couldn't play with her, but she was always wanting to play. So we picked that up in a very young age that she's actually really, really sociable, so we need to send her to mainstream and try to see if we can actually use this to benefit her cognitively, and you know. She is a four-year-old, but cognitively she's basically-- You’re looking at global development delay, and she is about, I would say, 15 to 18 months old, so we have to treat her as a 15 to 18-month-old kid. You know, you can't treat her as a four-year-old. She is a four-ager as well at times when she wants to see her YouTube and stuff like that. But when it comes to cognitively understanding stuff, she's very much an 18-month-old.

Q And am I right in understanding that [redacted]’s got a bit of a public profile?

A Yes, so she has been in-- So in her first two years I would say she had two pages of Google when you search, so she did have a lot of-- We did a lot of fundraising for her condition, so she was in in the public profile of various newspapers and stuff on rare disease stuff, yes.

Q And did she become the public face of a particular organisation?

A Yes, so recently-- That's right, so she has been-- This year, she became the summer-- For the summer appeal for CHAS, she is the face for CHAS basically. So CHAS do help us as well. We get help weekly, but now they're having a lot of difficulties with the end-of-life stuff so it depends when we can actually get help from them as well so-- But, yes, we do get a lot of help from CHAS. They've been great.

Q Thank you. Now what I want to do next is just to start to move through really the timeline of [redacted]’s treatment in the old Sick Kids in Edinburgh, and we will come eventually to look in particular at that incident in July 2019 that you alluded to a moment ago. Just to pick up on one thing that you've already said, and maybe just to set the scene, I think you said a moment ago that you have been quite successful at reducing the amount of trips to hospital, and I think we can see from your statement that really from about May 2018 to May 2019 you began to see quite a significant reduction, is that right?

A Yes, that's right.

Q And do we also see from your statement that in May 2019 [redacted] had an admission to the Royal Hospital for Children in Glasgow, is that right?

A That's right.

Q Now, I think it's clear from your statement that there were aspects of that admission that were not a positive experience, is that correct?

A Yes, it was not great.

Q I'm not going to ask you about that, but one thing I will ask you about is that I notice from your statement that when [redacted] was in the Royal Hospital for Children in Glasgow, you stayed in something known as Ronald McDonald House.

A That's right.

Q Can you tell us a bit about that?

A Yes, so we had gone into-- The Glasgow admission was because she was getting a heart monitor which monitors her heart, basically; put it that way. But some complications happened and she ended up in ICU, and we didn't have a good experience there, but that is a different-- I don't wanna get into all that. But the experience that we had really nice was at Ronald McDonald in Glasgow. It was great because, comparing to what we were experiencing in in Edinburgh, which we are so used to, we didn't actually-- That was like chalk and cheese, the difference for care.

Q And you've indicated you don't want to go into the issues around the clinical care in Glasgow, but I will ask you this question about it – you do say something about this in your statement: did your experiences there lead you to reflect a bit about the level of clinical care that [redacted] was receiving in Edinburgh?

A Yes, so if something like that would have happened in Edinburgh, we wouldn't have been-- It would have actually been looked after really well by clinical care, meaning the one thing that we have to put our hands up for, the services that we've actually got in the old Sick Kids as well as-- has been amazing, especially when she went for her gastrostomy. There was a multidisciplinary consultation where different departments worked around [redacted]'s care and that was just outstanding. I don't have any words for that. In terms of really good care, she got it.

Q Now, I want to move forward in time then to July 2019, and I think we can see from your statement that there was an occasion where

[redacted]had an issue with her breathing at home and you were required to take her to A&E, and I think ultimately she ended up in PICU in the old Sick Kids.

A Yes, yes.

Q Can you describe to us the management of [redacted]'s condition in the hospital on that occasion?

A Yes, so it all started at home. Basically we tried our level best-- There are certain things where you can actually-- If she's stopped breathing and my wife was basically giving her mouth-to-mouth and basically trying to respiratory-- You know, she did have a respiratory arrest at that point, and then we called in the ambulance and we basically went straight into A&E and they tried their level best to-- and she became even worse there, and that's how she ended up with a ventilator and taken up to the ICU.

Q And did they manage to stabilise her?

A Yes, they did. They were really good. They were actually-- They've been amazing all this while with the lack of facilities in that old place. But, yes, the clinical care has been amazing.

Q I'm going to come on in due course and ask you a bit about the state of the building and the equipment in it by that stage. But one thing I'll ask you about at this point is, it was obvious at this stage that there was about to be a move to the new hospital, is that right?

A Yes, so, as you had mentioned with me being a part of the

Family Council as well, so I was quite lucky to actually have a visit through the Family Council to the new place. This was before [redacted] got admitted in July. In mind, we knew that the new place is there, you know, facilities are there which will be good for her. There's separate cubicles, there's stuff like that for her, triggers can be kept. You know, this should be actually good for her. But, yes, so it was-- When she got into-- The care that she got out here, in old Sick Kids, was great. They did actually get her out of it, and she was getting discharged one day before the new Sick Kids was about to open.

Q I'm going to ask you a bit about that in a moment. Maybe just before we get to that, just to understand a little bit more about this day where she ends up in PICU, did you and your wife travel with her in the ambulance?

A My wife did.

Q And she was admitted quite quickly after that to the Intensive Care Unit?

A Yes, so they tried their level best to suction and they tried everything in terms of keeping her and getting her back. But she wasn't showing any signs of breathing properly or whatever, so she was then ventilated in A&E and then she was taken up.

Q Taken up?

A To critical care.

Q Yes. And by the next day, had they stabilised her enough for her to be discharged?

A Yes, so as [redacted] is, she herself pulled the ventilator out. She just didn’t want it in her mouth. She basically did get back to normal, which was great, and yes.

Q And so within about 24 hours, she was discharged back home, is that right?

A Yes, that's right.

Q What was the advice that was given at that time?

A So the advice that was given at that point was that, because of the period of the 24 hours of being discharged, it was, “If something does happen, not to come to the old Sick Kids A&E and to go to the new Sick Kids A&E in this 24 hours because we're shifting.” And we were given like I think-- Quite nice that we were actually given-- [redacted] was given a toy as well because there were so many things that they were given, so yes, she got that bouncy ball type of thing.

Q And that was because the hospital was closing, was it?

A Yes, yes.

Q So presumably after this incident, after [redacted] is discharged home, if something as dramatic as what had just happened happened again, you would have called an ambulance, is that right?

A Yes, we would have and we would have then actually gone to the new Sick Kids because we think that's actually going to open up, so yes.

Q It would be a question of-- I mean, we know that obviously the transfer didn't happen----

A It didn’t open, yes.

Q -- on this occasion, so it would be a question of whether the ambulance knew which hospital to go to, I suppose.

A Yes, I don't really know about the ambulance thing, but I knew that on the way-- It was basically through social media we came to know that it's not opening.

Q I'm going to ask you a bit about that in a minute, but this is prior to you finding out, you’re at a stage where [redacted]’s been discharged, you’re back home, you've been told if anything happens it’s the new hospital you go to. That may have involved a trip in an ambulance and that ambulance may or may not have known which hospital to go to, but were there occasions where, short of going to hospital in an ambulance, you would take her in the car?

A Yes, depending on how her condition is. So if she has a dystonia in the back and she's got an arched back, we can't put her on a seat, so it all really depends on how the condition was. But we also knew that the old Sick Kids is very close to our place. The quickest the ambulances actually reached the old Sick Kids from our house has been seven minutes, which has been great, seven to eight minutes, but we know now the new place is pretty far off, so we've got to go the length there. And you also have to keep in mind, like you asked that question about so many times the ambulance people have come, it becomes quite a shock when you actually say, "Oh, she's grown." The paramedics saying, "Oh, she's grown." Normally, you don't hear that from how regular they were coming, so yes.

Q So there's a relationship there?

A Yes.

Q And how long would it have taken you get to the old Sick Kids yourselves in your car?

A Yes, about 11, 12-- about 15, but with the ambulance, you can (inaudible).

Q Were there occasions though when maybe she hasn't really developed, you know, the episode hasn't fully developed into something as serious as requiring the ambulance? Were there occasions where, before it gets to that stage, you did take her in the car?

A Yes, so that was before-- I think it's the thing they have with below three, you have to take the child to Sick Kids. You know, it's good this thing that ambulance service do to take you to be seen. So this was before three, she was normally taken.

Q So if you----

A Many a times it has been improved in the ambulance as well.

Q And when you say three, does that indicate that there's a grading system?

A I don't know, but I've always heard that they would practice that. You know, it's safer in a way that a specialist sees the child more than not.

Q So if hospital attendance was going to be required, was it your usual practice to call an ambulance or did you ever take her yourselves?

A We took her ourselves as well many a times but, [redacted] being [redacted], she did deteriorate, and we had to call in the ambulance. Sometimes the ambulance was so busy that it took time. They came from the borders once, I remember. It was quite a wait, but mostly it's been very swift ambulance service.

Q In any event, the day after, or the day that [redacted] is discharged home, your understanding is, whether we're going by car or whether we're going in an ambulance, we're going to the new hospital, is that right?

A Yes. Yes, we were basically saying that if something does go wrong, my wife was more that, you know, it's going to be a longer drive. Even in the ambulance, it's gonna be. You know, they have a specific 60 miles or whatever, 70, they can't go faster than that. So we've got to keep in mind the distance and the-- You know, it's still going to take some more longer-- It'll take longer than the old Sick Kids, but we just have to go with the flow and see what happens.

Q And when was it and how was it you discovered that in fact you wouldn't have been going to the new hospital?

A Yes, so it was us either coming back or on the way, I don't really remember, I think I put it down in my statement, but it was through social media we came to know that it's not opening, the new place. And we then quickly gave a call to the specialist nurses who are for [redacted], and they themselves did not know what was happening. So we were basically in a catch what was gonna happen if something was wrong.

Q Up until this point, had you yourself seen signs that it looked as if the hospital was about to move?

A Well, yes. Everything was saying goodbye, like the whole walls were painted. I even wrote, "Thank you very much to the staff for [redacted]'s care," all that stuff. Then basically it didn't happen.

Q And what happened to all the writing on the walls?

A I think it was painted.

Q It was painted over?

A Yes, painted over I think because I remember a kid (inaudible), "I did write something here. It's not there anymore." The whole hospital has been painted, yes.

Q And how did you feel on discovering that the new hospital was not in fact going to be opening?

A I had two hats on at that point, one being a dad, first being the dad whose daughter has just been given care where they've told us to actually go to a new place and it's actually not opening, which we've got wrong information, and, secondly, the second hat been Family Council and how sad it is that Family Council themselves don't know what is happening.

Q I'm going to ask you----

A So what's the point in actually being-- Sorry.

Q Sorry, on you go.

A So what's the point in being a part of a Family Council where we ourselves don't know what is happening? So, yes.

Q Thank you. Now, let's move a little bit further forward with [redacted]'s care. I think we can see from your statement that in August 2019, it's paragraph 27 for anybody who wishes for the references – you don't need to look at your statement, Mr Behl – I think [redacted] experienced a problem with her swallowing in August 2019 and that required a further admission; that would be to the old Sick Kids, obviously, is that right?

A Yes, that's right.

Q Are you able to describe the experience in the hospital on that occasion?

A You mean the clinical side or the----

Q Just in terms of how the hospital appeared, so this is about a month after the cancelled move.

A Right.

Q To what extent had stuff that had been removed been returned?

A Yes, so basically it was still like – I've said it in my statement openly – a makeshift scenario. It was like they already had everything out. There were no toys, there was nothing in terms of, you know, in the wards. It was painted fully, the outpatient had changed, there was no-- WRVS had changed. You know, the food facilities were back to disaster again, put it that way, but yes.

Q If we just take one of the points that you just mentioned there, toys, I think we understand from your statement and from other evidence that we've heard that toys that had been provided to the children in the old Sick Kids had been removed prior to the move. Did you see whether those toys were returned?

A Well I did hear that they were asking for those toys. They did say that if someone wants to return the toys or something. I don't know if it was right or not, but there were no toys, I know that. To keep a child occupied, you need something to distract, and it was quite difficult, but yes.

Q So for a period at least

after the cancelled move, the children in the wards in the Sick Kids, to your knowledge, were without toys, is that right?

A Mm. Yes, it was without toys, but I think they did manage to-- I think it was maybe the charity that helped and, you know. But I know that when [redacted] was there, we didn't actually have anything. That's all I can say.

Q And was that problematic?

A Well, because we had, thankfully, cell phone which we had YouTube on there, so we managed to work it out. But if, say, a child was a bit bigger who wants to play PlayStation or something, it would have been difficult for them.

Q Now, moving a little bit further forward, I think we can see that there were regular visits to the hospital, the old Sick Kids, till about February 2020, and, of course, we're about to come into the COVID period.

A Yes.

Q But before we get to that, was there further discussion among staff or parents, or indeed anybody else, about the move during this period that you recall?

A Well, it became more of "Oh, the new place," you know. It just becomes a laughing thing, you know, saying, "I don't know when it's gonna open," type of a thing. But they did come up with a date as to when finally planning to open. But I don't think anyone knew that it was gonna open or not, but they did have a date, I think.

Q And I think we can see from your statement that, obviously with the COVID restrictions, between March and June 2020 I think that there were fewer visits to the hospital, is that right?

A Yes, that's right.

Q But I think we can also see from your statement, I think in about August of last year, there was a further respiratory arrest, is that right?

A Yes, she did have. Yes, that's right.

Q And, again, was there an admission to the old Sick Kids at that point?

A Yes, yes.

Q And did that require ventilation?

A Yes, it did.

Q And then I think there were some outpatient visits, is that right?

A Yes, so after that outpatient visits were there again. Things were a bit different with what the hospital was at that makeshift scenario, yes.

Q I'm going to ask you about that in a minute. But just before we get to that, just thinking then about [redacted]'s involvement with the hospital last year, thinking about the uncertainty about when there would be a move to the new hospital, did that create any anxiety for you or your wife?

A It did because we were told that, you know, there was-- especially with the new MRIs that are there, the machines and the DCN, the new DCN basically the imagery would be better for the technical side of what they were wanting to look for. But we just need to know that once the new place opens, the imagery can be better for [redacted]'s thing, but that never happened, so----

Q And then just maybe thinking about that a little bit further, and you mentioned earlier that you had a visit as a Family Council member to the new hospital. But are we right in understanding also that [redacted] herself has since had a visit to the new hospital?

A Yes, so she was the first one in the ward. I don't want to get into the names of the wards because I think anyone who has dyslexia or my daughter will never be able to pronounce that name of that ward because they're just castle names; all castles are the same colour, so what-- it doesn't play anything. But yes, so she was one of the first ones in that new place (?), yes.

Q I think, in particular-- was she the first person in the neuroradiology ward?

A Yes, she was.

Q And did she get something for that?

A Yes, I think she did. She, I think, got a certificate or something. Yes, she did.

Q Now, I'm going to move on now to the question of the facilities and the condition of the old hospital, and have you give some thoughts in relation to that. Let's begin with the wards in the old hospital. Which ward was [redacted] most often admitted to?

A So, she was in Ward 7, the neuro ward.

Q Can you describe that ward to us?

A Yes, the ward was-- meaning the staff knew [redacted] from five days old, put it that way. The ward itself, there was a cubicle which you'd share two beds for imagery, and then you've got one big room, which has six beds focusing with the nurse desk, and then you've got another cubicle which has four beds or something like that, yes. So, in total, they have about 12 beds I think.

Q 12 beds. And are we right in understanding that that's across three cubicles?

A Yes.

Q Were there any single bed cubicles on the world?

A No. So, we had to share whenever [redacted] did go into a cubicle. Sometimes you have to share it with the other child who's there or we actually using another ward, so we call it "bordering a ward". So, we basically using some other ward, neurology – especially when she's had a virus or something, you want to keep her separate from the whole.

Q Can you explain that to me?

A So, it's basically the times when she's been admitted with her episodes and stuff, and she's actually had a virus, you know, then she has to be kept in a separate cubicle.

Q Would she go into a different ward for that?

A So, she'd go in a different ward, so we called it, maybe, "bordering a ward".

Q Thank you. And in relation to occasions where she required monitoring, particularly EEG monitoring, are you indicating that that would be in a shared cubicle on Ward 7?

A Yes, so that was done in a shared, yes.

Q And in terms of other words that she went on to, are we right in understanding that she would, on occasion, be put onto Wards 4, 5 or 6?

A Yes.

Q And what sort of wards were those?

A Well, they were pretty big; they were different department wards, but she normally got the cubicle and, at times, we've actually had the video recording in those wards as well. So, the EEG team has put in the radio- - or the imagery, basically.

Q Were there ever occasions where it seemed to you that those other wards were perhaps not suitable for [redacted]?

A Oh, yes. We've had quite a lot of differences with their teams. They don't know [redacted], to put it very frank, and they don't know her condition. And sometimes it's been a lot of things with light. They say that, you know, you need to have the light on inside for the nurse to see everything, and you know, it's been, at times, explaining to them that, you know, the condition is such that, you know, if you keep the light on, she's going to go into a disaster. You know, it's explain that, and then finally it's been the specialist nurses coming in and explaining to the staff that we need to have this off, type of thing.

Q Yes. Are we right in understanding therefore that, on these other wards, there might be increased use of light, and were these other wards also a bit noisier?

A Yes, so I would say when we were in the cubicles, the noise wasn't a bit of a problem, but when we actually were in a shared area where you have other beds, like say four or six, then it could get a bit noisy. The word that I've used is a "Christmas tree", you know, everything is party time, the siblings running, all that stuff, and it depends on what-- You know, and every child would want to see their sibling, you know, and then meeting them in hospital and stuff, but for some kids, you know, it's a trigger.

Q Yes, I think you indicate in your statement that they were events arranged for children who were on the wards, and you say there were siblings visiting----

A Yes, yes. Yes. Yes.

Q -- and things could be quite noisy and quite bright.

A Yes. Yes.

Q Is that right?

A Yes.

Q But from [redacted]'s point of view, that that could be quite triggering for her, is that right?

A Yes, it can be. So, we were aware of that. We didn't actually take it up in a big way. We kept it to ourselves, and we basically tried to work around making sure that she doesn't get-- she's kept away from all this thing.

Q Now, let's move on to another matter, which I think you've already told us about, and that is medical equipment. Are we right in understanding that at least from the discussions that you had with nursing staff, there was a view that the equipment that you would ultimately get in the new hospital might be a bit more up to date than what you were getting in the old hospital, is that right?

A Yes, I think even the consultants mentioned it as well.

Q Do you want to tell us a bit more about that?

A Yes, so the MRI was one of the enhanced imagery that they have in the new places, like, world class compared to what they had in the old one, so that was one. Secondly, we've experienced ourselves, EEG that [redacted] got in the new

Sick Kids, the new hospital – it was just amazing, meaning we've seen such clear imagery that it's state of the art compared to the old place.

Q Are we right in an understanding that, in fact, on that occasion where [redacted] was admitted in July 2019, she had an MRI scan? Is that right?

A 2019?

Q At the old Sick Kids?

A Not in July, no, but she had one before.

Q Right. Now, the next thing I want to ask you about in relation to the old hospital is the arrangements for sleeping and catering for parents. And I need to ask you a preliminary question in relation to that: how did you arrange care between yourself and your wife when [redacted] was on the world?

A Yes, so that's a really good question. It's been quite a juggle, like you were balancing the coin in that aspect of food, because my wife was breastfeeding [redacted] for a very long time. She only got cereal as breakfast from the ward, and basically, she got no food. So, I had to basically juggle in sometimes pizza, sometimes Chinese, sometimes stuff, when sometimes the makeshift scenario was such that WRVS also shut, you know or you basically rely on going to Hugo – which the café, and you go outside and you basically buy something, like a coffee or something there.

Q Thank you. So, when your wife was breastfeeding [redacted], she would be with [redacted] more or less the whole time----

A Yes.

Q -- is that right?

A All the time. She was sharing the bed with her as well, yes.

Q And are we right in understanding, from what you've just said, in the morning, your wife would be given a bowl of cereal? Is that right?

A Yes.

Q And after that, was there anything else provided?

A No. At that point, I don't know what the situation now is, but there was formula milk given to kids who are not breastfeeding, but it's here where my wife is actually providing breast milk – she gets nothing apart from cereal, which I think is a bit of a-- You know, even at Family Council we have raised this up quite a lot as well, because you should be actually helping a mother who's actually feeding a child – because you do get quite thirsty, you get stuff-- In the new place as well, I did put in that, you know, there should be water or breastfeeding rooms. You know, that has to be there. Not just putting a chair there in a separate room and that's a breastfeeding room; you have to have a water source for mothers.

Q There's a few questions I want to ask you about that. First is this,

what, if any, breastfeeding facilities were there in the old hospital?

A I don't think there was any. She used to just, basically-- There was a room separate for the parent room, but you go into there and there'll be other parents sitting all there as well, which I don't know if you call that a separate room. There may be some mums who want to have privacy in terms of breastfeeding as well.

Q The second thing that I wanted to ask arising from what you just said: if your wife had wanted a drink of water while she was on the ward, would she have been able to get one?

A She would have troubled the nurse who would be busy at that point, but she would have asked them. Normally the nurses would get it, they never said no, but it's like, you know, they are busy with other kids.

Q Presumably there are sinks on the ward.

A No. Not drinking sinks, no.

Q And why was that?

A I don't know. I've never seen a drinking sink. I wish there was one, there was none.

Q When you say "drinking sinks", are you indicating that there were sinks but they were not for drinking from? Is that right?

A Yes, so the water is not-- it's only for hand washing. It openly says not to drink. There are signs there.

Q There are signs that say that?

A Yes.

Q Now, you've mentioned a few times that-- We imagine your wife stepping out of the ward and looking for some sustenance elsewhere. You've mentioned a few times the WRVS facility, and can describe that to us?

A Yes, so the WRVS was where the outpatients finally moved, out there, and then that was later taken on by the Edinburgh Sick Kids charity, they took over that shop. But yes, so that was a place where we could actually go and have a cup of coffee if needed, or maybe just have a small bite or something there. But that shut and finally we had to rely on the stairs which went up the cafeteria. Luckily, we are quite fine to use the stairs but for someone who’s in a wheelchair, next to impossible.

Q So, are you indicating, in relation to the WRVS facility, that that closed but was it immediately replaced by Sick Kids charity?

A I don't really remember what was before or after, but I know that, once the new place opened up, like, once they were not moving, they didn't have anything there.

Q Both of those facilities disappeared?

A Yes, yes. Disappeared.

Q Is that right?

A And it was just the Edinburgh charity having shop-- you know, the reception entrance, they had that. So, that was one-- well, the only place where we could actually get a sandwich or something, you had to----

Q So, after the cancelled move, that facility was still there, was it?

A Yes, near Ward 1, that was still there. That was where we got sandwiches and stuff, but because there were so many people buying stuff there, you know, sandwiches used to never last for that long, and we relied on basically chocolate and crisps.

Q Or, as you----

A Or go out.

Q To the Victor Hugo café.

A Victor Hugo, that's the one, yes.

Q Now, I think you indicate that there was a microwave on Ward 7, but was that really just for patients’ food?

A Yes, for staff and patients. We were not allowed to-- We can't (inaudible).

Q Yes. Now, let's think then a little about the facilities for children on the ward, and you’ve already told us a bit about this. Before the move, before the cancelled move----

A Yes.

Q -- before July 2019, what was your impression of the level of facilities and things to stimulate and interest kids on the ward?

A They did have stuff – meaning the staff themselves in Ward 7, playing nurse, she's just amazing. She's been with [redacted] since day one, so she had ways to entertain. And I have said this in my statement openly, is that-- it's the staff who basically made that place run. It's not even worth running that place, you know. It's basically hats off to the staff who actually made this makeshift scenario run. So, coming back to what, you know-- The toys and everything were there, but basically they had the art of entertaining kids.

Q And the person that you just mentioned, the play nurse, is that Audrey?

A That’s right.

Q What about internet access on the ward?

A Oh, it was next to nil, not there at all. Luckily, [redacted]’s not in the stage of wanting to, you know, cover up school-- nursery, school stuff, and homework. But there are kids who stay for 50 to 100 days in the hospital admitted, and they’ve got to do some work. So, hospital was a no-no when it came to Wi-Fi.

Q So, were you aware of that being a problem either from what you saw or perhaps through your Family Council involvement?

A Yes. Yes. With the Family Council, I knew that they were families who were having a tough time with the internet access when they had kids staying for 100-plus days in the hospital.

Q If you were to describe the condition of the old hospital overall by July 2019, how would you describe it?

A Again, makeshift. “Oh, there's a new place coming up, let's just not do anything to this place. The new place is coming, got state of the art stuff.” And it’s hats off to the staff who actually managed to run this for so many years. And they were really looking forward to the new place; they were more excited than actually parents, to be very frank. But I don't think they had a clue that it was not going to open.

Q Yes, I think in your statement, I think it's roundabout paragraph 45, Mr Behl – you don't need to look at it, it’s just to give others the reference – I think you described the hospital had essentially “limped along”.

A Yes.

Q And are you indicating to us that, really, it’s – as you put it – hats off to the staff for keeping it going for that long? Is that right?

A Yes. Yes. You get used to a certain, you know, surrounding and stuff, and that's what the staff were doing. They were basically just using what they actually had to run it. The new place is a different scenario, but we’ve stayed in the new place as well, quite a lot of times now. But yes, it's chalk and cheese difference in both.

Q And if we start the clock

at July 2019 and stop it at the point where the new place finally opens, staff, initially, must have been very disappointed on discovering that the move wasn't taking place. Is that right?

A Yes, it was. I did remember speaking, and you can laugh on it now, but it's like one or two did say “Oh, I bought my step calculator because it’s so much to walk there.” In the old place, you had no place to walk. But we were looking forward to the new place opening up and, you know, nothing----

Q But what did they do? Between those two points, July 2019 and the new place finally opening, did they just go back to keeping the old place going?

A Yes, just to keep the place going and they just ran the place the way things were. I remember there was a point where we were in the old Sick Kids just after the place did not open up, and we were wanting a syringe, which was basically because she has a gastrostomy, so we basically do a bolus, so we do a gravity 60 mils syringe. We were in A&E or somewhere, we were in one department – I don't remember the department – but we asked about, “Can we actually have a 60 mil

syringe?” And they said, “Oh, sorry, we don't have 60 mil syringes because it's all gone to the new place.” So, it was like, “Okay, so we just have to manage on a 20 mil, just trying to feed.” But that was just when the move didn't happen.

Q And you've said a few things already about the new hospital. I mean, overall, how does it compare to the old hospital?

A I mean, it’s totally different in terms of things are there. I mean, I've stayed in the new place-- I can only speak on [redacted]’s behalf. There are certain things which we thought would help her, but certain things you still have to play around for her triggers, like lighting can be one – like dimming the light on the path and whatever, has to be kept down. So, there are new small bits of things that are different, but I think it's still very much a world of difference between the old place and the new.

Q Thinking about some of the issues that you've identified with the old place, let's take one: the arrangements for having an EEG, are those improved?

A Oh, yes. The EEG rooms in the new ward, Borthwick, is really good. You’ve got, like, two rooms with really great cameras which are infrared, and they are state of the art. Even like the unit which they have out there is crystal clear video imagery you get, compared to what they had in the-- even they themselves have said, Brian and the team, it’s state of the art, what they have.

Q And it's no longer done in a cubicle where you're sharing with somebody else, is that right?

A No, they are separate cubicles for them, and they've also got a fold- down bed for a parent to sleep, and they’ve got an attached en suite as well.

Q Even in that room, where the EE----

A Yes, yes.

Q Yes.

A We were there for three weeks in the new Sick Kids, and in three weeks, you can come to know a little bit – things are not running well, but then that's a different----

Q Okay, I want to move on to a different matter now, and we’re moving really towards the conclusion of your evidence. And I want to ask you about an issue that is obviously very important in the evidence that you've provided to us in your statement, and that's communication.

A Yes.

Q And in particular, communication about the delayed move, the delay in July 2019. Now, prior to July 2019, what discussion had you been aware of about possible delays?

A You mean before July (overspeaking)----

Q Yes, before what you experienced in July.

A So, through Family Council, I’d done a trip to the new place. We went through each and every ward, and we went through each and every-- we went through Ronald McDonald, we went through all that, the cafeteria, and we went through catering. And we knew that the new place is opening up, because you didn't know that it was never going to open up at that point, so we were in minds that we actually would be-- You know, if something does go wrong with [redacted], we know that the new place is there which has got state of the art (overspeaking)----

Q Whether with your dad’s hat on or your Family Council hat on, was your position that you weren’t aware of any doubts or uncertainty about the opening of the new hospital?

A Yes, till the day it was “the next day it’s opening”. I mean, we were in hospital, and we were getting discharged, and openly when the staff out there said "Look, if anything goes wrong with [redacted], do not come to this place. You have to go to the new place because that's where she'll be treated."

Q Okay.

A So, yes.

Q Now, let's then have you think a bit about the communication that you did receive after the move didn't happen, and I'll do it in the way I've just done it; let's, first of all, have you tell us a bit about looking at that from the point of view of being [redacted]'s dad.

A Yes.

Q Now, you've already told us about the social media message that you got June or around about that time, is that right?

A Yes. Yes, that's right.

Q And was that from a friend?

A I don't remember. I think it was my wife having a look at somewhere in Facebook or somewhere she looked at, and it basically was a pop-up thing that the new place is not opening.

Q Okay, and can you recall whether you received any official communication around that time?

A No.

Q I think in your statement, at paragraph 56, Mr Behl, you indicate that there was possibly a letter about three weeks later, is that right?

A Yes, that's right. We did get one saying that if all appointments and outpatient appointments and stuff need to go to the old place, not in the new one, yes.

Q And presumably, when you and your wife were back in the old hospital after July 2019-- presumably there would have been discussion on the ward with nursing staff and other parents and that sort of thing. Is that right?

A Yes. Yes, so not much in terms of speaking to families at the time when [redacted] was admitted because you just say "Hello" and "Hi" to other families because they are themselves having a tough time with their own kids. But with Family Council, we did do a survey with various wards, and we went around asking families about what they felt about the shift, the new Sick Kids, and we got-- I don't remember the whole thing, but we did actually send-- I can't speak from the Family Council on my own right now, but I think we got really interesting feedback from families.

Q Okay, I'm going to ask you in a minute about the Family Council angle on this, but just thinking about you being – after the cancelled move – back in the old hospital as [redacted]'s dad, or your wife being there as [redacted]'s mum, was there much discussion with the nursing staff, for example, about what was actually going to be happening?

A Yes, we did. We used to always ask that, you know, "Have you got any information about the new place?" And they said, "No, we just don't know anything. We are just basically waiting. It'll open, but there have been some problems, you know." And they just said, "some problems." I said, "Oh, that's fine." But we had more problems to ourselves with the child, you know, so we didn't ask much about it. We knew that it was not opening, so that's about it.

Q And was your impression that the nursing staff didn't know either?

A No, I don't think so. I think I did hear that one or two did actually head to the new place, knowing that it's not opening. I don't know, you'll get this when you do your nursing thing, I think it will be quite interesting to see the feedback.

Q Okay. I now want to ask you then about the communication with the Family Council.

A Yes.

Q And before we do that, can you tell us a bit about the Family Council, what it is, and when you yourself became involved in it?

A So, I'm a new kid on the block, put it that way. Once [redacted] was born, we were so regular into admissions in A&E – that's where I saw on the board saying that, you know, "Be a part of Family Council" and my wife was the one who said, "I think you'll would be quite good at joining the Family Council." So, I did get in touch, and I think it's been about two and a half/three years now that I've been a part of the Family Council. But the Family Council has been there for many years. As bluntly as put it like, you know, they are the ones who represent families that they've never ever met, you know, and they basically look into-- It's not like a complaining type of platform, but it's more in lines to looking at, you know, services and things for families to improve in hospitals.

Q And are the members of the Family Council all parents?

A Yes, they're all parents. You have five of us.

Q And are they all parents of children who are presently involved, or can it include those who've been formally involved with the hospital?

A Yes, there are some which are, at present, using the children's hospital, and some have actually been there for so many years and basically their kids have now gone into adult.

Q And even just roughly, how many members are there in the Family Council?

A Five to six. Five/six, yes.

Q And how regularly do you meet or communicate?

A So, yes, we communicate regularly. And also, we've been meeting-- used to meet Fiona Mitchell, she was very into the Family Council and work with us before the place opened up.

Q And she was the Director of Women and Children's Services for NHS Lothian, is that right?

A That's right. That's right.

Q Was there – as you understood it – an official liaison or communication on a regular basis between the Family Council and NHS Lothian.

A Yes, that's right.

Q And was she the conduit for that?

A Yes, we used to have lots of meetings at Rail Bank(?), one of the offices there in 1 Rail Bank, near the old Sick Kids. We used to have meetings there, about four or five times we had had there, and then we've actually-- post COVID, like once COVID hit, I think we've had lots of Teams meetings with the NHS teams as well as us.

Q If we can, I'm not going to ask you to try and cast your mind back to specific family council meetings, but just to try and get a sort of general understanding of communication about progress on the hospital, let me just take this in stages. If we think about the position prior to July 2019----

A Yes.

Q -- so, prior to the cancelled move, the Family Council members themselves, in your regular meetings and discussions, have been discussing what progress there was on the move to the new hospital?

A Yes, we've been discussing with the team about updates in terms of the when, "When is actually the place going to open up?"

Q And is that something that you, through the Family Council, would have been discussing also with NHS Lothian?

A Yes. Just the team with Fiona and the team, and they're about five/six of the people there as well as us, all discussing about the new place. That's what all of the minutes was, looked into various things of, you know, the parking, the accommodation, the catering, all that – looked into it.

Q So, what you're calling “the team”, did that comprise Fiona Mitchell and some colleagues from NHS Lothian?

A Yes, that's right.

Q And they would meet regularly with your team.

A Yes.

Q And are you indicating that that would involve discussion of the state of the old hospital?

A No, it was mainly looking at the new place and looking at how things are going to be taken forward. Yes, this was happening before the July 2019. And suddenly it gave a shock(?).

Q That's what I'm getting at. So, in these regular discussions, are we right in understanding that there would be a discussion of what the new hospital would look like and what facilities there would be? And were they looking to you to get some input in relation to that?

A Yes, so they were taking inputs for catering. One of our Family Council colleagues went into WaverleyGate, and looked into all the menus and has actually spoken to Lord Brodie about it as well. And that was basically brought up about what his involvement with the catering side of things. As well as-- We looked at the parking, looked at accommodation, looked at into what new things can be there that-- in the new place, basically.

Q And so, presumably, the Family Council members would be able to say, “Well, here's our experience of things that are suboptimal in the old hospital.” Is that right?

A Yes.

Q “These are things that you might want to think about doing better in the new hospital.”

A Yes.

Q So, parking, food, that kind of thing.

A Yes, so there was the free parking, that used to give 50 cars or whatever that was given, now it’s given to disabled kids when they come and, you know----

Q And during those discussions, presumably there would also have been updates on progress.

A Yes, absolutely. So, we used to get progress updates from the team, and Angela Riley(?), and others – I don’t want to name names, but yes.

Q I mean, I know it's difficult, but how regularly would you meet with the team?

A I would say once in three months.

Q So, every three months or so.

A Maybe four months, I don't really remember that, I can look into it.

Q So, if we take July 2019, there would have been a meeting, at least within the last three months, is that right?

A Yes, yes. I remember that meeting.

Q And can you say whether, at that meeting or at any prior meeting, the Family Council had been given any indication that the move in July was not going to happen?

A No, we were not told anything. We would think the place is opening up. Actually, when we went for the tour, it was just before July 2019, where things were absolutely fine. We were looking at-- The only thing that I proposed was the names of the wards because, you know, a person who has dyslexia or something will not be able to pronounce those names ever in life. I know my daughter will not be able to pronounce her ward name in life. But yes, that was what we basically covered.

Q Yes. And did meetings with the team, with Fiona Mitchell and her team, continue after July 2019?

A Yes.

Q Can you recall whether at those meetings there was discussion about why the hospital hadn't opened?

A Yes. So, we did approach saying that “Why were we not told? I mean, what's our role in terms of not knowing?”

Q And what was their response to that?

A I don't really remember their response, but I think it was more like I don't think they even knew as well.

Q Well, let's just take this in stages. Let’s separate two issues. There's the issue of why the hospital hadn't been opened, issue number one; issue number two is the issue of why the Family Council had not been told. Let's take issue number one. Were you given any explanation after July 2019, through the Family Council, of why the hospital hadn't opened?

A No, not through them but we came to know about what the news reports have actually said. That's what we got, that the new place had not opened (overspeaking).

Q Would the Family Council have seen its role as including trying to get an explanation?

A We did. We did ask for that, but I don't think-- I don't remember what actually happened in those meetings, but I don't think we were given any-- We were just given what basically has been publicly told what has actually happened.

Q Did you indicate earlier that those meetings are minuted?

A Yes, they are.

Q And do you know who holds the minutes of the meetings?

A I think it was the secretary, or it was basically Fiona and the team.

Q You think the minutes sit with NHS Lothian rather than with the Family Council?

A Yes. We don't have-- It’s with NHS Lothian.

Q So, that's issue number one, the question of why the hospital didn't open. You sought an explanation, and your recollection-- well, you're not sure but, presumably, if you had been given an explanation, you would be able to tell us about that.

A Yes. No, I don't really know that the explanation-- I don't know about it.

Q And what about issue number two, then: the reason of why the Family Council had not been told anything about this prior to July 2019, what was the explanation for you not being told?

A I just vaguely remember it was that they themselves didn't know so, basically, we were the last people who ever would have known.

Q Okay. I want to move on now and have you perhaps just tell us a bit about the impacts on various people as a result of the delay and, in particular, the cancelled move in July 2019. Before we get to you and your family, what about impacts on other families either that you were aware of through the Family Council or that you just saw as being on the ward? Did you see other families being impacted?

A I think some of the families who rely on Sick Kids quite a lot-- like for us, we're very fortunate that [redacted] doesn't stay for that long in treatment because we manage most of it at home. There are kids who stay for 100-plus days in hospital, so for them it's a very big impact; they would like to know what's happening. And that's what I basically remember getting back as feedback in Family Council. I think that was the main side of things, that to know what is actually happening;

the uncertainty of not knowing.

Q And what about impacts on [redacted]? I mean, in what way did the delay impact upon [redacted]?

A With [redacted], she herself doesn't know what was actually happening, but for us, as a family, we knew that we had a strong team around on [redacted] in terms of various departments, and she has a multidisciplinary unit which communicate, and in those ways and whatever happens, we'll just follow their guidance where we have to. But keeping in mind that, you know, we were always-- the state of what the old hospital always gave in terms of trying not to have too much of triggers for her and stuff, we always had that in our mind, and we tried to stay away from all that. Even our consultant has so many times said that "It's best that [redacted] can manage at home. That's great because this environment is not right for her."

Q And is that something that you've actually been reasonably successful at achieving?

A Yes.

Q And do we see from your statement that you've had some assistance in relation to that from NHS Outreach? Is that right?

A Yes, that's right. So, we get help from NHS outreach. They go one-to-one for nursery for [redacted]. So, [redacted]basically goes with a carer from NHS Outreach. They are the Band 4, they're not Band 6 for nursing; they aren't nurses, basically, but they're carers, but they can actually give her medications and they can actually give her – if she does have a seizure or she has an episode in school, in nursery – then they can actually look at giving emergency drugs to her.

Q So, just really moving towards the very end, I'll ask you this question. But thinking about what you've said about the hospital that was limping along even before July 2019, and thinking about your awareness – by that stage at least – that some of the equipment that was being used was not state of the art on your evidence, and thinking also about what you said about after July 2019, that there was some equipment not actually available, did the delay to the move cause you or your wife any anxiety?

A I think it did. It certainly did in terms of not knowing that-- because we were told we're going to get an MRI, and we were looking forward to the MRI and the new machines that was in DCN. But that never happened, so that was a very-- Like, I mean, it would have improved something. I don't know if it would have improved or not, but still hasn't had the MRI, put it that way. But maybe, at that time, an MRI was needed in whatever condition she was in, and that is something which we were always in a question mark: "What's actually happening?"

Q Thank you. Mr Behl, I have only one further question for you, and it's simply this: are there any other observations or overall comments you would like to make about your experience of the delayed move to the new hospital?

A I think it was mainly the communication, lack of communication between management and patients' families. At least let us know what is actually happening, especially the ones who come regularly for appointments and stuff. You know, you need to know where you're heading to. You rely on special help. As we started this inquiry where you have, basically, he said that every day is a new day for us. We don't know what the next hour-- what [redacted] is going to do, her condition. And that's her condition, you know; we live with that. So, knowing that we have a safety net behind us, the hospital and the staff, and we know the staff is great, but they need to have certain cushion around them as well to give us that thing. That was something which was not there for us.

MR DUNCAN: Thank you. My Lord, I have no further questions for Mr Behl.

THE CHAIR: Thank you, Mr Duncan. And thank you very much, Mr Behl, for your written statement and for coming here and giving evidence. It will be, as you will understand, part of a large body of evidence, but we've heard less about Edinburgh than Glasgow, so you made a particularly useful contribution.

THE WITNESS: Thank you.

THE CHAIR: Thank you, you are now free to go.

THE WITNESS: Thank you.

(The witness withdrew)

THE CHAIR: Now, Mr Duncan, I think the plan is to take the next witness not immediately but remotely. Is that----

MR DUNCAN: That is correct, my Lord. My understanding is that the witness herself will not be available before midday, but my understanding also is that there will require to be a period just to test the connection, and I think it might be around half an hour or so.

UNKNOWN SPEAKER: (Inaudible)

THE CHAIR: (After a pause) Right. Well, that's good to hear. So, we're aiming for about 12 o'clock, and we'll sit again then.

11:20

(End of the Morning Session)