SCOTTISH HOSPITALS INQUIRY

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Hearings Commencing
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10:00

THE CHAIR: Good morning. Ms Arnott, we begin with Mrs King; is that right?

MS ARNOTT: Yes, my Lord.

THE CHAIR: All right. (After a pause) Good morning, Mrs King.

THE WITNESS: Good morning.

THE CHAIR: You are about to answer questions from Ms Arnott, who I think you have maybe just had the opportunity briefly to meet?

THE WITNESS: Yes.

THE CHAIR: Good. I don't know how long your evidence will take; maybe much of the morning, maybe less than that. We will take a coffee break about half-past-eleven, but if at any stage you want to take a break for whatever reason or no reason, just tell us and we will do that.

I think you would prefer to affirm; is that true?

THE WITNESS: Yes.

THE CHAIR: Thank you very much. Ms Arnott?

MS ARNOTT: Thank you, my Lord.

Mrs LESLEY KING

(Affirmed)

Examined by Ms ARNOTT

MS ARNOTT: Mrs King, I'm going to begin by leading you through a formal questions this morning. Can I begin by confirming that you are Lesley King and that you live with your husband and two children in the Edinburgh area?

A In Midlothian, yes.

Q Okay. And can I ask, Mrs King, what is it that you do for a living?

A I work for a conservation charity.

Q And do you have some experience as a project manager in your past history?

A Fifteen(?) years as a project manager.

Q Mrs King, I wonder if you could bring your microphone slightly closer to you. Thank you. I understand you're here today to give evidence about your daughter; is that right?

A Yes.

Q And your daughter is currently eight years old?

A That's right, yes.

Q Thank you. In October 2018, when your daughter was five years old, I understand she was diagnosed with neuroblastoma; is that correct?

A That's right, yes.

Q And she was treated in

the Royal Hospital for Sick Children in Edinburgh; is that correct?

A That's right, yes.

Q Okay. And I believe she was treated there from October 2018 through to May 2020?

A That's right.

Q And your has attended check-ups at the Sick Kids Hospital until March 2021, when she was transferred to the new Royal Hospital for Children and Young People in Edinburgh; is that correct?

A That's right, yes.

Q Thank you. Mrs King, you've provided a detailed statement to the inquiry about your experience and your daughter's experience and I understand you are content for that to form part of your evidence to the Scottish Hospitals Inquiry?

A That's right.

Q Thank you. You've also come along today to answer some more questions about certain parts of your experience; is that right?

A That's right.

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

A Yes, I do. Yes.

Q If you want to look at your statement at any point as we go along just to refresh your memory,

please do so. I may also ask you to read certain parts of your statement as we go. Okay?

A Yes.

Q Thank you. And before we go on to talk about your experience and your daughter's experience, could you start by telling me a bit about your daughter before she was diagnosed?

A She's quite a mellow character, quite an easy-going child, very sporty, very outdoors, loves nature a huge amount, out on her bike or climbing or walking or all sorts of things.

Q Thank you. Mrs King, I'd like to begin by thinking about the events around your daughter's diagnosis up to the point that she was admitted to the Edinburgh Sick Kids Hospital. Could you describe the circumstances of your daughter's diagnosis?

A The main thing had been a sore tummy. She'd been sent home from school a number of times with a sore tummy. One night in particular, she was up in agony for hours on end. I'd given her Calpol and all sorts and nothing seemed to bring it down. So we went to the GP the following morning. The GP checked her over, couldn't find anything wrong with her.

Gave a urine sample. Unfortunately that got-- the lid wasn't on so that had spilt, so then a day later they asked us for another urine sample. Then they phoned us up and said that was looking a bit strange, could we come back in.

Another GP looked at her. Again, couldn't find anything particularly wrong, thought it might be a virus of her adrenal glands and said it should come down in a few days, the pain should go away, but said if it got worse or it didn't go away then we should go to the A & E because they might be able to check her out some more. They didn't think it was appendicitis at that stage, but it was one of the things that they were thinking might be an issue.

I'm thinking Monday was when we went to the first GP and it was the following Tuesday we went to A & E, eight days later, and at A & E they did an ultrasound of her and they found a mass. (Witness upset)

Q Mrs King, please take a moment. (After a pause) Are you okay to carry on or would you like a short break?

A Yes.

Q Okay. And was it at that point you were in A & E at the old Edinburgh Hospital; is that correct?

A That's right. Yes.

Q Yes. That was around the beginning of October 2018?

A It was-- oh, gosh, 3 or 4 October, I think it was. Yes.

Q Okay. Am I right in thinking that that day you were sent home but told to come back to the Oncology Department the next day?

A Yes. Yes. So, it was my husband that took her to A & E and it was one of the-- it was a haematologist that came and spoke to him and said----

Q Okay.

A -- "Look, we need to see her the following day."

Q Okay. So you went back into the old Children's Hospital at that stage?

A Yes.

Q And was it at that point that your daughter was admitted to Ward 2 in the old hospital?

A She was admitted that following day, but later on. So, in the morning we went in and we met an-- her oncologist. Lily wasn't feeling very well. She wouldn't let her touch her. But the doctor was able to say without even touching her that she definitely had cancer. And so they took blood samples at that point and sent us home, said they'd be back in-- I think we were to come back the following day because they would have a better plan then. But they phoned us that afternoon and they said there were-- there were signs in her blood that something was going wrong and they needed to see her immediately and could we come right now. (Witness upset). Sorry.

Q It's quite all right, Mrs King. Please just take your time.

A Yes. So, there were signs that her organs were beginning to fail and they were hopeful that the blood sample was incorrect and so they wanted to take a repeat blood sample just to check, told us not to worry but to come immediately. It was at that point she got admitted to hospital. I think we were there for about a month at that point.

Q Okay. So, she was admitted to hospital at that point. They had some idea of what was going on.

A (No audible reply)

Q I understand from your statement they carried out some further tests, I think----

A Yes.

Q -- some scans and a bone marrow sample?

A Yes, exactly. They knew it was cancer----

Q Okay.

A -- they just needed to know which one it was----

Q Okay.

A -- and the extent of it.

Q Okay. And I understand from your statement that in terms of the very, very initial treatment before they made, I think, a full diagnosis, your daughter couldn't be fitted with a Hickman line at that stage, but she was fitted with something called a femoral line; is that right?

A Yes, that's right. Yes.

Q Yes. Just describe what that is, please.

A Essentially it's into the femoral artery just at the top of your thigh. She couldn't have a Hickman because there was too many tumours in her neck. The femoral line is something that can last for up to about 10 days and still give them options of going direct to the blood supply, rather than having to do a cannula, which has to get replaced every single day.

Q But the femoral line, as I understand it, still has to be replaced every day days or so, I think you said?

A Yes. It has to be done under anaesthesia.

Q Okay.

A And it has to be-- it can only last for so long before there's too much of an infection risk and has to be removed.

Q Okay. And was it at that stage, Mrs King, that you received a diagnosis, a fuller diagnosis?

A Yes. So she would-- we first-- we went to A & E on the Tuesday, she was admitted on the Wednesday and on the Friday we were given the neuroblastoma diagnosis.

Q Okay. And was that a stage 4----

A Yes.

Q -- high risk diagnosis?

A Stage 4, high risk neuroblastoma.

Q Mrs King, what were you told at that stage about your daughter's treatment plan?

A So, they gave us a standard approach which at that time was a 9-month treatment plan, so it was going to be eight rounds of chemo, it was going to be an operation to remove as much mass as they could from her abdomen, then it was going to be high-dose chemo in isolation and then it was going to be radiotherapy and immunotherapy.

Q Thank you, Mrs King. I think I take from what you've just said that it was a detailed and carefully planned----

A Yes.

Q -- treatment plan to try and tackle what was going on with your daughter?

A It's a standard protocol at that stage for neuroblastoma is what they put in place.

Q Okay. And I understand from your statement that your daughter was admitted as an inpatient at that stage?

A Yes. Yes, she was.

Q And I think you've just said a few moments ago that she was there for about a month, about four week for the first inpatient----

A Yes. I mean, at that point, we didn't know how long she was going to be in for, it was until they could get her stable.

Q And could you tell me a bit about how you arranged being with your daughter in the hospital, how you split it between you and your husband?

A The first week one of us would stay each night, the other would try and stay as long each day as they could. We had my other daughter, but we had to-- we packed her off to my mum's, had her looked after there. So, people were coming and going during the daytime as visitors but us, as parents, were trying to be there as much as possible each day. At some point we started to try and split our time at hospital so we could spend time with our other daughter, who was finding it very strange and confusing. We'd try and have one day at hospital, one day at home, do it that way round.

Q Okay. So it was a kind of turn and turn about arrangement?

A Exactly. Yes.

Q Thank you. Mrs King, I think that would be a good point in your story to pause and think now about the old Edinburgh Sick Kids building itself. And for those following the statement we're at paragraph 12; you don't need to look at that, Mrs King, it's just to give the reference.

Could you begin by describing where the old Sick Kids is located?

A It's in Sciennes Place, so it's just off the Meadows in Edinburgh.

Q And was it easy to access?

A For us, yes, by car. Yes, it was easy for us to get to. It's about 20/25 minutes' drive for us.

Q Did you have any issues with parking there?

A A lot. So, it's all on meters around it and for one car each day it was about £22 to £27 a day. We'd put on one of the phone apps and just keep feeding the meter, basically. We did, at some point, get given some vouchers which would give you so many hours of free parking a day. Unfortunately at that time we often had two cars at the hospital because of the back and forth that we were doing. It cost a huge amount of money at first. And I think we forgot and got tickets. One time I parked in a visitor's bay by accident and---- It cost an awful lot of money.

Q So that wasn't a very straightforward experience?

A No. I mean, finding a parking space is fairly straightforward, but yes, it was remembering to pay.

Q Okay. Thank you. And just thinking about the building itself, just from the external façade, how would you describe the old building?

A A big, red Victorian-- I mean, the wards themselves are like Nightingale wards, I think, originally set up. So big high windows. Do you want to talk about the ward or just the building?

Q I will come onto that, Mrs King. I'm thinking just as, you know, you approach it now, what is it you see? Is it an old-style building?

A Oh, yes, it's a big, beautiful red sandstone Victorian building, quite imposing at first. The A & E side is the modern side and is a big ugly and unpleasant to go into.

Q Okay. Thank you, Mrs King. You've indicated in your statement that your daughter spent, I think, the majority of her time in Ward 2----

A Yes, that's right.

Q -- in the old Sick Kids; is that right?

A Yes.

Q And I'm going to ask you now to describe the ward and then we'll move on to think about the rooms specifically and the facilities on the ward. But just thinking about the ward itself, I think you've already described it as a Nightingale ward; what do you mean by that?

A It's basically one big 'L' shaped corridor. As you first go in there's a series of rooms off each side, which are the Teenage Cancer Trust beds, there's treatment rooms, there's private consultation rooms, doctors' rooms and so forth and then you turn the corner and you go into the ward itself. And along one side is just beds with curtains round them, very much like you'd expect in a Nightingale ward, with a central place for nurses and administrative staff to sit at. And then on the left hand side there's a series of cubicles have been knocked up. They're kind of glass with wood frames on the door and each window has a blind that you can pull down if you----

Q So those are, if I understand you correctly, they're not originally intended as individual rooms, but they've been a kind of temporary structure----

A Exactly. Exactly.

Q -- a makeshift structure----

A Yes.

Q -- within the ward?

A Yes.

Q Okay. And how many cubicles were there, do you recall?

A There's six cubicles.

Q And you've indicated that there were some other beds within the ward which were open but with curtains that could go around them?

A Yes.

Q What were those for?

A The first-- God, I think it was four beds were day-care beds, so the kids that are getting things just done during the daytime and they go home at night. And then at the end there's another two beds that were overnight beds if the cubicles were full, you'd stay in those beds overnight with a curtain round you.

Q Was there, in terms of

your impression, was there much privacy for the day-care beds?

A No. No, there's no privacy. I mean, occasionally a curtain would get pulled round. But, no, it's all done in the open.

Q Okay. Okay. Thank you. And does that mean if you were staying in the cubicle rooms one of the private-- more private rooms were there a lot of day-care patients coming and going on the ward?

A Oh, yes, yes. It was entertainment for us. We could sit and watch what was going on out there. But the cubicles didn't really give any privacy either because they were all glass-fronted and the blinds had to be up during the daytime.

Q Right.

A It was a goldfish bowl.

Q I think you mention in your statement there were also two treatment rooms there?

A Yes.

Q And perhaps you could describe those for us.

A A bit like a dentist's room, to be honest. There's a bed in the middle. All round the side there's various cupboards and fridges and suchlike. Equipment gets brought out when it's needed to be done. There's also the computers in there for the nurses checking up on what treatment is needed when and where.

Q Thank you, Mrs King. I'd like to ask you now some more questions about the individual patient rooms or cubicles, as you've described them. You've already described that they have a glass front; does that mean they were entirely glass on the front?

A Yes. So they're smoked glass from the kind of waist down and there's clear glass above that level.

Q And to your recollection did each of these rooms have windows?

A They have windows out into the car park, yes.

Q Okay.

A No, one of them didn't have any windows outside.

Q One of them was, effectively, an internal wall, or a wall?

A Yes. It was where it was positioned was kind of at the end of the corridor and it had-- there was a window outside in the toilet, but not in the actual room.

Q And are you able to give an indication of the size of these rooms?

A There's enough room for a hospital bed, two chairs, there was a sink and there would be one of those little cupboards for putting your clothes and essentials into. Essentially, the size of a double bed plus a bit of space at the bottom.

Q And can you recall whether all of the rooms were the same size or did they vary?

A Oh, no, they varied in quality. There was a hierarchy as to which room you wanted when you came in. Room 1 was the biggest room, because there was room for chairs to be out during the daytime so visitors could come and visit you, but it was the room next to the treatment room so it was the noisiest room in the whole place. Rooms 2, 3, 4 were similar size. Room 5 was the one that had a toilet, so it was a good room but it had no window to the outside world, and then Room 6 was actually a really good-sized room with a bathroom en-suite, so you could stretch out in that one.

Q I think you describe Room 6 in your statement as the high-end room; is that right?

A Yes. Yes.

Q Okay. So I think what you've described is there is a variation in quality and facilities within each of these rooms and it sounds to me that what you're saying is that each had its own pros and cons?

A Yes. So, Rooms 2, 3 and 4 were very, very cold in winter, but were quieter. They were very, very hot in summer. We just-- when we went to hospital we'd be texting back and forth with my husband just saying, "Okay, it's good, we've got Room 1," or, "It's bad, we've got Room 4" or----

Q It was a bit of a lottery?

A Definitely, yes.

Q And just to come back to the question of bathrooms within the rooms, did any of the rooms have en-suite bathroom?

A Room 6 had an en-suite bathroom. It had a bath and it had a toilet in there.

Q Was that the only room that had a full en-suite bathroom?

A Yes. That was the only room.

Q Did Room 5 have a bathroom of any kind?

A It had a toilet.

Q And Rooms 2, 3 and 4, which I understand were in the middle, did they have any kind of bathroom facilities within?

A Nothing.

Q And what about Room 1?

A Nothing.

Q Nothing. It was only two

rooms out of the six have any kind of toilet facility in them?

A That's right, yes.

Q Okay. And given what you've just said, what were the bathroom or toilet arrangements for the ward?

A There was two toilets for patients at the end of the ward and there was a bath in a separate room at the end of the ward and children would go back and forward and use them. The difficulty was that they would generally be attached to a drip stand, which are very heavy, and the challenge with a lot of the treatment that they get is that children are overdosed with-- well, they're often fluid positive, they're given a huge amount of fluids to wash chemo through, which means when they need to go to the toilet they need to go fast. Often little children who don't have the same, they can't hold it as well as an adult can. So we rarely ever used those toilets because we didn't have the opportunity.

So there was a commode that could be pushed up and down into rooms. We didn't use the commode because it's very hard to get it into the room when there was chairs in the room for visitors, plus trying to get the drip stand out, so we brought a potty from home for my daughter to use.

Q Are you indicating that it was difficult to get the commode into the rooms because of the size of the rooms?

A Yes.

Q I think you say in the statement that sometimes if you wanted to use----

A Yes.

Q -- if the commode was needed the chairs had to come out or the door was partially open?

A You could get the commode in the door and get the door shut just about, but the commode would only get to the end of the bed. So you'd have to then hold the drip stand up a long-- in between all the chairs, it's like a bit of guddle. You then get the child to the commode. So if they're attached to any form of drip stand it was very difficult to get them onto the commode.

Q So it wasn't an ideal solution?

A No. And you'd have to find the commode first, which might involve a run up and down the corridor trying to find the commode and the child needs the toilet immediately.

Q It's not the case that there was a commode for each of the rooms?

A No.

Q There was a limited number?

A I think there were two commodes, but one would spend its most of the time along in the Teenage Cancer Trust section. There was one for the other four rooms that had no toilet.

Q Okay. Thank you, Mrs King. Could you describe to us what else you would see in the room as you walked in? I think you mentioned earlier there was some furniture and some storage?

A Yes. So there would be a cubicle for putting bags and clothes into. There would be two chairs during the daytime for visitors to sit in. There was a pulldown bed like a camp bed for the parents to stay in that was folded away to the side and then there was a hospital bed for the child.

Q Okay. So when you say there was a camp bed for parents there, are we to understand that is a portable camp bed that could be brought into the room and put off to one side?

A Exactly, yes.

Q Did that take up much space in the rooms?

A During the daytime it was folded up and out the way. At nighttime we had to remove the chairs from the room to put the bed down and we'd put the chairs into the corridor. The bed could be out but we've have to push the bed back up again by about eight o'clock the following morning.

Q Okay. So if you were going to stay overnight it involved a bit of shuffling the furniture?

A Very much so.

Q And the chairs would have to come out of the patient bedroom and into the ward, is that right, at night?

A That's right, yes.

Q Okay. Was there a television in the room or anything like that?

A Yes. Yes, there was a television and a DVD player and there would be these PlayStation type things that you can bring in that were in the playroom.

Q There was some entertainment for your daughter, then?

A Oh, yes.

Q I think you've already mentioned the temperature of the rooms, but could I ask you to tell us a bit more about that?

A It varied greatly. So in winter it would be very, very cold. The windows were old metal frames and would often be very, very draughty. At one point we sellotaped a window shut. In fact, later on, the hospital actually paid for someone to put a silicone gun and glue the window shut because it was so cold in winter. So we'd often have extra blankets. At one point we got a few heaters in to try and keep us a bit warmer. Windy days were particularly cold days, because the wind would whip round the courtyard and come in through the windows.

In summer it would be incredibly hot in the rooms. You could open the windows when we were allowed. There's a small window at the bottom that you could open a crack, but it wasn't enough to give you any kind of airflow through the rooms. And because of the way the sun was coming in these windows what we'd often do is pull the blind down during the daytime to stop the sun coming in and try and cool things down a bit.

Q I think you indicate in your statement as well that you would, depending on the time of the year, try to get the best cubicle that would suit the time of the year, depending on the temperature; is that right?

A Yes. Yes. We definitely had targets as to which cubicles we were aiming for when we came in.

Q Okay. Thank you, Mrs King. You've mentioned there were camp beds for parents to stay over that could be used in the rooms. I'd like to ask some more now about the facilities for parents and families that were on the ward.

A Yes.

Q Now, you've mentioned there was a bathroom for children on the ward. Was there a bathroom or toilet for parents to use on the ward?

A Until COVID, no. Adults had to leave the ward and go deeper into the hospital to find a toilet.

Q And how far away was that from the ward?

A A few minutes' walk. Not far. Not great at 3am when you're in your pyjamas wandering the halls of a hospital.

Q And you had to physically leave the ward to go and find at bathroom?

A Yes. So there's a click button to get off the ward and then when you wanted to come back on the ward you had to press a buzzer to be allowed back in. If you came back at a busy time you could be stood at the front door for a while before you were allowed back in.

Q The effect of that was that you would potentially have to leave your daughter alone for quite a period of time----

A Yes.

Q -- just to go to the bathroom?

A Yes. For the toilet it wasn't too bad. For the shower it could be quite a long time I'd be away for.

Q I was going to come on and ask you about that next, Mrs King. I think you mentioned something called PJ's Loft----

A Yes.

Q -- in your statement. Could you tell us about that?

A So the very attic of the building has been given over to parents. There was bedrooms upstairs, there was bathrooms, there were showers. There's a kitchen, sitting room. I think that was supported by a charity. But you'd need to go to reception to get a key, a pass, and then it would be a lift to the fourth floor and then you'd walk up a small set of stairs to get up into PJ's Loft. If you took the lift it could take a very long time, because you're then fighting with children in wheelchairs and the likes, or you'd have to walk up four or five stairs, four or five flights, to get you to the top.

Q So, again, it was a bit of

a journey to get to PJ's Loft----

A Yes.

Q -- if you wanted to go there?

A It was nice to get a bit of exercise. But, yes, I reckoned even with a very fast shower I'd be away for 20 minutes.

Q I think you've mentioned as well there were some bedroom facilities in PJ's Loft; is that right?

A Yes, for parents that have come from far away, they try and find them a bedroom if possible.

Q But you didn't have to use those facilities because you were a bit closer to the hospital; is that right?

A Yes, thankfully we could just----

Q And I think you've mentioned there was a sitting room there as well----

A Yes.

Q -- within PJ's Loft?

A Yes.

Q And was there also a launderette facility?

A Yes, there was a wash-- two washing machines and a drier.

Q Okay. And just in terms of your general impression, what condition was PJ's loft in?

A Unfortunately it was

falling apart. A lot of the showers didn't work or would only have cold water. We got to the point where we worked out which room, the one you try and aim for and generally there would be someone in there when you got up there. So you'd have to go to one of the cold showers or try and use a bath, which takes time to fill. Yes. They'd done their best to maintain it, but it was falling apart. The windows wouldn't seal up there. They were rotten at the seals.

Q Okay. Thank you, Mrs King. Thinking back to Ward 2 now, were there any kitchen facilities on Ward 2 for parents to use?

A Not for parents, no. There was a kitchen that was for the staff and the children and parents were not allowed in there and they were meant to ask one of the nurses or auxiliaries to heat up food for them. They were allowed to store food in the fridge, but you had to ask one of the staff to get it out of the fridge for you and heat it up for you.

Q Okay. So you really had to use up the staff's time if you wanted to use the kitchen facilities at all?

A I have to admit after a while I bypassed the staff and just went in by myself, because we'd been living there so long at that point I felt

like I was part of the furniture.

Q Okay. And if you wanted just a cup of tea or coffee, what was the arrangement for that?

A You were allowed one tea in the morning that was provided to you by one of the auxiliary staff and you'd be allowed one tea in the evening at about eight/nine o'clock. But in between that there was no provision for----

Q So other than that you would have to leave the ward----

A Yes.

Q -- if you wanted anything to eat or drink?

A Yes.

Q And what were the facilities off the ward in terms of getting something to eat or drink?

A There was a little literally just outside the ward. It had sandwiches, drinks, snacks, odds and ends that you'd forgotten when you'd came in from home, shampoos, shower gel, that kind of thing. There was a canteen – I only went to it a few times, quite awkward to get to and clearly more of a staff canteen that parents were allowed to use. And then downstairs, down at A & E, there's another little shop that was down there that you could get a hot cup of tea.

Q Thank you. And thinking now about the facilities on the ward for entertainment of children, could you tell us what was there?

A Well, there would be a play specialist every day who would have various activities for the children to do, painting, crafting, things like that. There was also a playroom at the end which had various board games, books, crafting things in there, toys for the little kids. And then there was a big stack of DVDs that you could take back to your room and there was these PlayStations, X-Boxes, that kind of thing, for bigger kids that they could take away as well and use.

Q And was there any other entertainment provided by charities or anything like that?

A Yes. We'd quite regularly get someone coming in so there was singing therapy, I think, once a week, there was a lovely artist would come round and do things every now and again, December in particular was chock full of fun people coming by and doing fun things with the kids.

Q Okay. And did your daughter use these facilities quite a lot?

A As much as she could, yes. Whenever she could go out the room she'd be in there.

Q And were siblings allowed in to use any of these facilities as well?

A Yes. They encouraged family to bring in siblings as much as they could. They recognised that children-- it's an alien environment and they wanted to be around their family. So there was an open policy for visitors, they were allowed in whenever they wanted and weren't sent home until sometimes, like, nine o'clock, ten o'clock before some visitors left.

Q Okay. Thank you. I think you mentioned in your initial description of the ward that there was also a Teenage Cancer Trust facility. Now, I know you weren't using that, but are you able to tell us anything about it?

A Yes. There was I think two or three beds, separate rooms along there. They had a kind of common sitting area that their beds came off. And they had a dedicated staff member for them that was there to talk to them and hang out with them and help them as best they could.

Q Okay. Thank you. And before we move on, Mrs King, you mention in your statement one particularly positive aspect of your experience, and I think that was in relation to the nursing staff on the ward; would you like to say anything about that?

A They're magnificent. They became like friends to us. Yes. Staff were magnificent. They took us in, they looked after both my child and my family.

Q I think you say here that your daughter had-- I think it was almost a one-to-one nursing ratio?

A Yes. By and large she would have-- for each shift you'd be told which nurse was dedicated to you. Sometimes you might get a nurse to two cubicles, but a lot of the time I think for the kind of treatment that my daughter was on she tended to have one nurse dedicated to her for the shift.

Q I think you indicate in your statement that you felt they were very responsive every time you had to press a buzzer or anything like that?

A They were like a military operation the way in which they could work out that they put a chemo up, it was going to be four-hour bag therefore it was going to start pinging at a certain time, therefore they'd get the next bag ready of what was needed to be done and they'd sort their shift breaks around all of these different treatments that would be going on and, yes, they were wonderful.

Q And I take it from what you've just said that, again, planning is a very important part of chemotherapy treatment?

A Yes.

Q And military precision?

A It's meticulous what they have to do, because often one piece of treatment needs to be followed by the next needs to be followed by the next, so they have this very clear plan in their heads as to when things are going to be finished and when the next thing---- Because only so many of them are allowed to hang chemo because it's a, you know, it's a poisonous toxin that you're hanging, so you have to through various processes to get authorised to use this. So, they'd have to make sure that the staff that were authorised to use this would be available at the times when the next bag needed to be hung.

There was additional treatments like if she needed painkillers then had to go and be authorised by someone. If there was a morphine drip then you have to have the Pain Team come round so many times a day to check that things are as they are meant to be. It’s incredible to watch. You can see that level of quality project management in their heads as to what they’re doing.

Q And I think you describe in your statement that you felt the nurses were very specialised in that ward?

A Oh, massively so.

Q Yes.

A Massively so.

Q Just thinking again about the general procedures on the ward, then, were you aware of any particular cleanliness or hygiene protocols or procedures on Ward 2?

A Yes. So there would be cleaning staff come round each morning. They’d start with the cubicles. I think from about 8 a.m. you’d start getting the cleaning staff in and they cleaned down every surface in the room, as well as clean all the entire floor. Then they clean the main areas of the ward.

When a child moved out of a cubicle every single piece of furniture would be taken out of that cubicle and it was given a deep clean. All the furniture was given a deep clean before put back into the room. So you’d have a-- there would be a turnover period between each cubicle, a child leaving and the next child coming in.

Q And were there protocols around handwashing?

A Oh, yes. As soon as you come in the ward there’s a sink there; you must all wash your hands when you come in the ward. Every time they touch-- before they touch a child they had to wash their hands and after touching a child they washed their hands. If you were touch-- if you were having to deal with things like pee, poo, vomit you had to wear orange-- sorry, purple gloves if they were on chemo because they’re extra thick gloves. For other purposes it would be the normal thinner blue gloves if they were giving treatment. But for the most part it was purple gloves on as much as you could for the risk to your own skin of touching some of these chemicals.

Q And what was your understanding of the risk that was being controlled on the ward through these procedures?

A So very early on you understand the immunocompromised nature of these children. Essentially, the treatment they’re getting removes a huge amount of the function of their immune system. They are at high risk of-- the normal little bugs that are on your skin would be highly risk to these children. So a common cough or cold is actually a really dangerous thing for these children. So, yes, a lot of it is about trying to control that risk to them and infections from them. So that's why the handwashing goes on.

Staff would wear masks if they had a cough or a cold and, obviously, since COVID those restrictions have gone up even more to the point that you're wearing masks the whole time.

Q And was that risk of infection something that, as parents, you were acutely aware of from the beginning on the ward?

A Yes. So very early on in treatment you're sat down and you're told all the things you can and can't do and pretty much you can't do a huge amount of things. So from the simplest of things like a playpark with woodchip on the floor you can't go near because there's a fungal risk of infection there. Soft scoop ice cream, you can't have that because of the risk of listeria from that. Someone coming into your house with a cough or cold, people not removing their shoes in your house, everything was a risk. Yes.

Q Okay. Thank you, Mrs King. Mrs King, I'd like to now come back to think about Lily's treatment as

we move through the chronology of that and I think the next stage of her treatment began in November 2018. I think you say in your statement after the first four weeks of intense treatment your daughter was discharged but she was still in and out of hospital as a day patient; is that right?

A From October to December she was on a chemo treatment that was every ten days she'd get chemo. Chemo would take three or four days to give her. She'd come as an inpatient for those three or four days, go home for three or four days and then come back in for the next set.

Q Thank you. And in your statement you describe a particularly bad experience you had in November 2018, I think, when your daughter was admitted to Ward 3; would you like to tell us about that?

A This was she was finally able to get a Hickman line, so I think she'd had three femoral lines up to that point and they finally decided that her tumours had shrunk sufficiently to allow them to fit a Hickman line. Again, this is under anaesthetic a surgeon was going it, but because it was a surgical procedure she had to go to the surgical ward afterwards, which was Ward 3, and that's very, very different to Ward 2. I think it's surgery and burns there.

But it's a much bigger number of beds up there for children and you're mixing in with parents/children who might have just come in to have their tonsils taken out or, from my perspective, what was a fairly minor surgery. For them, it might be the only time they've been in hospital with their child and it's obviously very stressful and worrying, but it was like being in a bit of a zoo, to be honest, because the sheer number of people that were in this place and the sheer number of visitors they had coming in and they perhaps weren't aware of the risks of infection to my child. They came in and so it was very, very stressful.

Q I think you say in your statement the ward was a dormitory style ward but there wasn't much space between the beds; is that right?

A Exactly. So there was, I think, three or four cubicles, but they were set aside, I think, mostly for the burns patients. But on the rest of it, yes, you had a bed then there would be a chair, there would be a bed, there would be a chair, bed and a chair. I don't recall curtains. There must have been curtains, but I don't-- never pulled. But, yes, you were cheek by jowl with other people.

Q Were there arrangements in that ward for parents to stay over?

A There were beds for-- camp beds for some of the patients' beds, but not for all of them. I'm told that previously they had had parent beds for every single patient bed but a staff member had tripped over one and broken their leg so they'd removed some of the patient beds. On that occasion, there wasn't a parent bed next to my daughter, so they put, I think, five or six parent beds up in the playroom at the end, like we're having a sleepover together at the end. I could come back and forth and see where she was.

Q I think you indicate that at one point your daughter spiked a temperature, I think, and was moved into a cubicle; is that right?

A Yes. So, I'd come back and forth during the night every half an hour or so just to see how she was doing. She'd had surgery, she was scared, she was upset about me not being next to her. And then I finally fell asleep and when I came back she wasn't in her bed. I'm told that she'd spiked a-- they'd tried to take her to the toilet because she was-- I think she was attached to a drip and she was in pain, and whilst there she was sick and then had spiked a temperature. So they'd moved her into a cubicle but hadn't told me.

Q Is that because you were in the kind of camp out room at the end of the ward?

A Exactly, yes.

Q Mrs King, thinking now what you said about infection control procedures on Ward 2, how did that compare to what you saw on Ward 3?

A Completely different. Completely different. I'm sure the staff were washing their hands as and when they needed to, but parents and children were not respecting that distance. In Ward 2, every single child and every single parent there knows the risks there are of infection and so are very good about giving you that space and making sure there are adhering to that kind of infection control, but Ward 3 was-- well, it was completely different. People and coming with McDonalds wrappers and just talking loudly on the phone and touching things around you. No, there was no-- not from the parents and the families.

Q So from your perspective, Ward 3 was not a suitable environment for an immune-compromised child?

A It causes a lot of anxiety that place, yes.

Q Mrs King, I'm going to move on now to think about December 2018, moving through the chronology again. I think you indicate in your statement then that there was a brief pause in your daughter's treatment; is that right?

A So she had eight rounds of chemo and then did various scans to see how she had progressed and whilst there had been a reduction it hadn't been as much as they'd hoped for and so there was a lot of back and forth with the Surgical Team to try and find out---- The next stage had meant to be her going for surgery, but the surgical team were not happy to do the surgery, they declined to do it, they thought it was too high risk. So there's a lot of discussion about what they could do in order to get her into surgery. And so during the discussion period they proposed a round of a different type of chemo, did another set of scans, went back to the Surgical Team who said no, gave her another round of this chem, went back to the Surgical Team, they said no and we ended up doing this four times.

Q I think you indicate in your statement, as you've just done, that there was a tension between what the oncologists wanted to do and what the Surgical Team felt was best to do and it took a bit of time to iron that out?

A I mean, they very much work as a team and they're balancing out risk of-- you know, the probable risk to the child. The Surgical Team had said that the risk was too high that she would bleed out on the table.

Q I think you indicate at that time there was no plan in place, there was a bit of a hiatus in the treatment, but then you come into the period from January 2019 and there was still no firm plan in place, but I believe your daughter's stem cells were harvest then; is that right?

A They knew they were going to be doing this other stage of treatment later down the line, so this was-- and that needed the stem cells for that and the stem cells take some time to be prepared in order to undertake that treatment, so they did need to do this at some point and so this was seen as a good time to do the stem cell harvest.

Q Okay. And at that point there's still some debate about the exact best course in terms of treatment?

A Yes, exactly. We didn't know whether we would get the surgery before we go onto the next stage of treatment or whether the surgery might come after. There had been some evidence about it being successful after the high-dose chemo, there's some evidence to show that it really needed to happen before that and so a lot of back and forth with the team at that stage.

Q I think you indicate in your statement that after more debate and more discussion and more planning your daughter's case was presented to the national neuroblastoma team; is that right?

A That's correct, yes. That's bringing all the experts across the UK together who understand neuroblastoma to give us advice and they showed that recent evidence said that the surgery didn't need to remove everything. If the surgery could remove as much as possible, then they had a better outcome for the child. So, that was when they returned to our Surgical Team who said, "Right, we're willing to have a go at this but we can't remove everything," because the way the tumours were wrapped around her arteries it was too much risk for there and they didn't want to take those pieces out.

Q And so am I right in

thinking that at that point it was agreed surgery would go ahead and it would be followed by a very high-dose chemotherapy; is that right?

A That's right. Yes.

Q Okay.

A That's right.

Q And I think you indicate in your statement that your daughter had surgery on 3 June 2019; is that right?

A That's right, yes.

Q And could you tell us some more about that?

A It was a very, very long day. I think it was seven hours in the end she was gone for. They'd done a lot of planning in the lead-up to it, but at the same time they won't really know until they opened her up as to what it was going to look like. They came to us and they said they thought they'd got maybe 90 per cent of the tumours out from her abdomen during that surgery, which is a huge success. They said when they went in, in it being like concrete they were chipping away because the chemo had clearly worked on the tumour. So, I think they spent quite a lot of time just trying to work out what they could take away without causing risk to her blood. They took a kidney because one kidney was just enmeshed in tumour.

The other kidney they left, even though there was tumour around it, but they said she needed one kidney to function. And, yes, they just tried to take as much as they possibly could that day.

Q And am I right in thinking that after that your daughter was admitted to the Intensive Care Unit for a couple of nights?

A That's right, yes.

Q And then you returned to Ward 3 briefly?

A Yes.

Q And then back to Ward 2?

A We begged them to move us back to Room-- Ward 2.

Q And was that because of your concerns about Ward 3 that you've already outlined?

A Ward 3 is-- it's a-- yes. Part of it is about the concerns of infection, part of it was about lack of sleep and just how unhappy we all were, my child and us as parents. It's like a conveyor belt of children going through operations in there and recovery is hard work in there because it's loud, it's noisy, it's bright, people coming and going in your face the whole time.

Q And I think from what you've just said, I take it Ward 3 just wasn't a good facility for families to be in?

A Oh, no. No. No. Children were the consideration, not the families, considering what it was built and designed for, it was built for children to be dropped off at the door and picked up a week later.

Q Mrs King, I'd like to think now about the next stage of your daughter's treatment, so this is after the surgery and as we move through June 2019. In particular, I want to think about how this had to be planned and then how it had to be scheduled around the move to the new hospital. I wonder if you could start by telling us what was the next stage of your daughter's treatment?

A The next stage was to be high-dose chemo with stem cell rescue. So, that's using the stem cells they'd collected a couple months earlier. Essentially, it's one week of very high intensity chemo which would reduce her immune system completely, take it to zero, puts her in a very high-risk situation of infection, but also a number of other complications that could potentially happen. There was a lot talking about the timing as to when they do surgery, so when would she have recovered sufficiently from surgery to cope with

the next level of treatment. And then there was the-- we had to start to then deal with the mechanics of where it was going to happen, because the hospital was going to be moving during that period. So, the best time of when to give it wasn't necessarily the best time that would cope with where we could do it.

And so, there was a bit of discussion at that point as to how they were going to take this next piece of treatment forward. Because high-dose chemo is such a high risk for the child, they have to spend their time in isolation after it, in a room that has been even more clean than normal rooms are, that has limited access so that only medical staff can come and go, and only one parent can be with the child during that period. So, they needed to manage the risks that were going to happen to her from this treatment.

Q Thank you, Mrs King. I'd quite like to explore some of that in more detail. What I'd like to do is begin by asking you to read a paragraph from your statement, if that's okay. Mr Russell, could we bring up paragraph 41, please? (After a pause) Mrs King, do you have that either in hardcopy or on the screen?

A Yes, I do. Yes.

Q Could you read paragraph 41, please?

A

> "The plan was that she would have five days of one type of chemo, an hour's blast a day. She would be an inpatient, so she had to sleep overnight in the hospital, but was allowed out in the afternoon to go to play parks, or go for a walk, so long as she'd return to hospital at night. The next step was for her to get a 2four-hour infusion of this other chemo. At which point, she would then be confined to her hospital room. The day after this she would get her infusion of stem cells and she would be in isolation. She would then be in isolation until her neutrophils rebounded. This can take a couple of weeks, or it can take several weeks; it all depends on the child and whether there are any side-effects."

Q So, can we take it from that that this was a complex plan, it had to be very carefully timed----

A Yes.

Q -- within days? I mean, there was no wriggle room here.

A No, once the train has left the station, you carry on. There's no stopping that treatment,

Q I think what you've indicated as well-- Mr Russel, thank you, we can put that down. You've indicated as well that there was an added complication with the clinical team, which was the planned move to the new hospital. Now, can you----

A That's right.

Q -- recall what the date for the planned move was?

A July----

Q It was 9 July, is that right? 9 July 2019.

A It was going to be either one week or two weeks into her treatment, depending on when they started.

Q And I think you indicated a moment ago that you recall there being some discussion within your daughter's clinical team about the timing and the interaction between that move and the treatment----

A Yes.

Q -- is that right?

A Yes.

Q Can you recall what was discussed?

A Some of the clinical team thought she would be best just going to Glasgow for the whole period because there would be no disruption. Some of the staff wanted to keep her in Edinburgh, but to change the timing of her treatment, so delay it by a week to cope with the hospital move. So, essentially the first week of this chemo was the lowest risk for her because her neutrals hadn't then dropped. The second week was the highest risk; so, the hospital move, at that time, would've been two weeks into her treatment if they followed the plan as, medically, she needed. So, there was that discussion as to whether we go to Glasgow, deal with the kind of additional complications there is for a family dealing with a child who is 50 miles away, knowing that-- And it's a very intense period and parents are very, very tired and scared, want to be with their child as much as possible, or stay in Edinburgh but cope with this move of hospital and therefore delay the treatment by a week to cope with the move, so that the move would happen during the lowest risk period for her.

Q How did you feel about the possibility of going to Glasgow for the treatment?

A We weren't keen on going to Glasgow. We were aware of other people who had been coming back and forth to Glasgow. Mostly just because of the physical disruption of trying to see and be with your child,

you're talking a long drive back and forth when you're tired; so, we weren't keen on doing that. We weren't aware-- we'd heard mutterings at that point from a few parents, but we weren't particularly aware of any other risks of going to Glasgow.

Q So, your primary concern about Glasgow was really the disruption and the practicalities of it, but you'd heard some rumours in the background.

A Yes, that's right. We'd heard people saying they didn't like it, and they were coming to Edinburgh instead of going to Glasgow because they much preferred what was here. I think we'd heard a couple things about the building, but it wasn't our focus.

Q No, and were those concerns mentioned at all by the clinical team or were they really just thinking about the timing and the practicalities?

A No, it wasn't mentioned by the clinical team.

Q And what was the ultimate outcome of the debate around what should happen with the treatment and the timing of it?

A They decided to keep her in Edinburgh, but they decided to delay her treatment by one week to allow us to cope with the hospital move.

Q I think you've indicated just a moment ago that that would be because your daughter's neutrophils would not yet be at their lowest point. So, it was timed----

A That’s right.

Q -- to move her at the safest time in her treatment.

A As safe as they could, yes. Delaying treatment is a risk, moving her during treatment was a risk, so they had to take the balance of probabilities of which one would be the better option for her.

Q I think you've indicated that there was a delay of a week in starting her treatment because of the planning around the move, is that right?

A That’s right. That’s right.

Q Okay. How did you feel about that decision?

A Everything is scary. Everything is scary during treatment: not treating her is scary; treating her is scary. You had to have faith that the staff that we were dealing with had her best interests at heart, and I do have that faith in them. But they treated her as if they were-- Every time we'd have that discussion, they said “If this was my child, this is what I would do.” Which is a very useful way of trying to understand their concern for your child, that they it really did care for my child.

Q Thank you, Mrs King. I think you indicate in your statement that, despite your concerns about the delay in the treatment and the move, there was a potential upside to the move, and you'd heard some positive things about the new children's hospital. So, I am going to pause there and ask you some questions about that----

A Yes.

Q -- if that’s okay.

A Yes.

Q When had you first become aware that a move to the new hospital was a possibility?

A I think potentially even when she started treatment it was on the cards. I'm from this area, so I knew hospitals were being built. I didn’t know exactly when. I think there'd already been one delay actually, the opening. But yes, I think from the very beginning we knew there was going to be a move at some point to a new hospital.

Q But you weren't quite clear, at the very beginning at least, when it was going to be.

A No, not the exact date, no.

Q But then, as your

daughter's treatment plan was being discussed, it came into quite sharp focus exactly when the move was going to be, so it was planned around that, is that right?

A Exactly, yes.

Q Okay. And I think you indicate in your statement, and this is at paragraph 45 for those who are following, there was quite a lot of discussion among the staff at the hospital about the new hospital, and there was some anticipation about it. Can you recall what those discussions involved?

A Oh, there was months of lead-up to this. The staff were getting taken in groups for visits to go and see the facilities and see what it looks like, and they'd come back and tell us what they'd seen; the cleaning staff in particular because they had to have the hospital cleaned three months in advance before it could then be opened. They were spending quite a lot of time over there. And the nurses would come back and tell us about the size of the room, the shapes of the room, what the facilities would be like for the children, facilities for the parents. They talked about how much easier it was going to be to do treatment, and how they had all these brand new machines and tools that they were going to be using. Yes, a lot of excitement in the lead-up to that move.

Q Did it sound like quite a significant improvement to what you were experiencing at the old hospital?

A Massively so, massively.

Q You also mention in your statement that there was going to be a garden.

A Yes. Yes, straight off the ward there was going to be a garden space specific for the oncology, haematology children that was going to be wheelchair friendly, was going to have benches, green space. Apparently, there was a helipad as well, they could watch helicopters if they wanted.

Q So, did you think that was going to improve your daughter's experience considerably to have the garden there?

A Hugely. Hugely. Being allowed outside was rare because there were steps down out of the hospital and, if they couldn't walk-- I think one time, at Christmas time, we had a pipe band come and play and someone had to help carry me, the child, and the drip stand downstairs so we could go and see a pipe band. It's very hard to leave the ward once you're in.

Q But your understanding of what you've heard about the facilities at the new hospital that it would be much easier to leave the ward and there would be more facilities and more entertainment there.

A So, there was going to be private rooms for each child, and the rooms were going to be big enough that there would be space for a parent bed – apparently it was really comfortable. There would be chairs out so that visitors could come and go with ease. There was going to be a wonderful big playroom full of brand new toys and equipment. There was going to be a parent kitchen. There was going to be a parent space where you could sit and have a cup of tea and have five minutes' break from it all. Yes, it sounded like the Shangri-La to be honest.

Q And was your daughter aware of what she was going to be getting?

A Very much so. Very much so. She listened to everything. She's got little satellite dishes listening to every conversation.

Q Was she excited about it?

A Very much so, yes.

Q And apart from the facilities that you'd heard about the

new hospital, I think there was one particular thing that you were quite focused on that you mention in your statement, and that was the prospect of specialist isolation rooms; is that right?

A Yes. So, in the old hospital you were literally just one of the cubicles off the ward, people coming and going right outside. But when you moved to the new hospital, if you're doing a high-risk procedure like that one, you'd be in an isolation room which was off a separate corridor. I believe there was two sets of double doors between the ward and this isolation room.

Told the isolation room had positive pressure, which essentially means outside there was not going to be coming in as it would be pushed out through the ventilation, so reducing airborne infection risks. And because it was a brand new building, brand new room, it would be much easier to clean all the surfaces once they were in there as well, so a number of infection risks could be better controlled from this room.

Q So, from your perspective, did you feel that your daughter was going to be safer going to the new hospital because of these facilities?

A Very much so, yes. We knew that high-dose chemo is very risky and has a lot of complications, and so the thought that this new room was going to be there and she would be the first person in it was a real comfort that this would help to manage the risk for her.

Q And to your knowledge, when the clinical team was discussing the treatment plan options, was the existence of this facility part of that decision?

A I don't know about its existence. They would have managed her-- You know, if she’d started a month earlier, they would have managed her in the old hospital. The main focus, I think, had been about the timing of when to move her. Yes, the room would have been wonderful if it was there, but treatment happens no matter what.

Q Okay, thank you, Mrs King. So, overall, would you say that you had high expectations at the hospital?

A Massive. Yes, massive expectations.

Q Did you think it would have improved your family's experience as well?

A There was only one concern we had, and that was about the parking situation. We were now at the point where we had a blue badge, and we could park for free at the hospital. Children on cancer treatments are highly discouraged from going on a bus for transport, so we needed a car to get her to and from hospital. But we were told, the new hospital, we'd have to pay for parking. It would be £7 a day so, at that point, family and friends were trying to work out a way in which they could get a kind of system set up where they could take us and drop us off and avoid us having to pay.

Q In your statement, Mrs King, you mention one other potentially positive aspect about the move, and that was in relation to the CLIC Sargent facility. Can you tell us about that?

A Yes. CLIC Sargent’s now called Young Lives vs Cancer, but it's a charity that provides a dedicated social worker for each child going through treatment. When we started treatment with my daughter, they'd had a house directly opposite the hospital which had drop-in facilities for people who live nearby, but for people who lived far away, there was bedrooms for them to stay with their family. Some children are coming as far away as Orkney to get treatment, and so the whole family comes down with them. That house had got sold and had moved over to the new hospital; it was about five minutes' walk from the new hospital. We knew that, when we moved to the new hospital, we'd be able to access that house and its facilities, which we hadn't done up to that point at all.

Q Thank you, Mrs King. I want to think now about the events in July 2019 themselves. Had you observed preparations for the move?

A Oh, massive amounts of preparation. Yes. There'd been a lot of stock that had been moved over so that, you know, the cupboards of all the equipment-- there was enough to get us through the next few weeks, but they'd taken a lot of that stock over to the new (inaudible). Things like obs machines were coming to the end of their time, and so we had the older sets at the old hospital, but we knew, at the new hospital, there was sets of new equipment there ready to be used.

The playroom got packed up completely, so all the toys were removed, all the DVDs, everything like that was taken away. In fact, there was an awful lot in the skip outside which people had taken things from. So, that had been shut up and, yes, there was just a scaling back of the kind of peripheral support; the medical stuff was going on as normal, but the peripheral stuff was scaling back. I think the shop downstairs had shut and things like that.

Q And in terms of your impression, were the nurses on the ward quite heavily involved in some of these logistics?

A So, what you ended up seeing was more staff each day. So, you'd still have the standard number of staff for doing the medical support, but there'd be additional staff on shift that day to support the moving of the hospital across.

Q And I think you say in your statement, it made no difference to your daughter's care from your perspective, in terms of the nursing care that she was provided?

A There was one issue when the chemo fridge was switched off and she missed a day's chemo, but whether that was due to normal accidents that happen or whether that's just the chaos – I don't want to say "chaos" – but it was busier than normal in the ward as things were coming and going, and there was more staff involved.

Q Thinking again about your daughter's treatment at this point, I think you indicate in your statement that she began her high-dose chemo, which you described as “super strength”, I think, in your statement----

A Mm-hmm.

Q -- but she began this super strength chemo, I think, on 1 July 2019, is that right?

A (Inaudible) the exact date, but yes, July.

Q Thereabouts, okay. And she was in an inpatient in Ward 2 at this stage.

A Yes, yes.

Q That was all part of the agreed treatment plan.

A That's right, yes.

Q Okay. What happened on 4 July 2019?

A My husband was in, and he phoned me, and he said, “It's not happening, they've cancelled the move.” He said he'd been taken aside by one of the nurses and said, “They don't know anything more, just that it's not happening – they cancelled it.”

Q Can you recall what time of day that was?

A I’d say afternoon, but no.

Q But really that's all he’d been told was it was not happening?

A Yes, really minimal information. The nurses tell you everything – if they didn't know, we didn't know.

Q So, am I right in thinking your husband was given no indication as to why the move was not happening?

A No. No “whys”.

Q Did you see any stories in the press about it at this time?

A Yes, yes. They were saying that it had been cancelled, yes. And the Minister for Health was asking questions.

Q And we'll come back to that a bit later on in your evidence, Mrs King. How did you feel at this point?

A Scared. Scared. We didn't know what this meant. We knew she was staying in the hospital, and we knew they’d do the best they could, but we’d been promised we were going somewhere that was going to try and manage those risks.

The room that they would normally have used for this procedure had another child in it who was very long term in the hospital, so at that time there was no room available to do this in, and that room had not been treated yet to cope with the process. And a lot of equipment and materials had been shifted to the new hospital. So, yes, in a period of significant flux, my child was in serious risk. Scary.

Q Okay. Thank you. I

think you indicate in your statement that, as part of your turnabout arrangement, you were in the hospital the next day.

A Yes. Yes, that's right.

Q And were you told anything about what was happening then?

A Rumours. Rumours at that stage that it had been stopped at the last minute. We didn't know why it’d been stopped at the last minute, but it wasn't ready to accept children and therefore it wasn't happening.

Q And was that rumours among the parents, from the nurses?

A Hard to distinguish between the two, to be honest, probably from staff.

Q Just chatter on the ward?

A Yes.

Q I think you also say in your statement that there was a visitor to the ward that day. Is that right?

A Yes, the Chief Exec of the Sick Kids was there. The Chief Nurse came and asked me did I want to come and speak to him and talk about this, and I declined. I didn't know what was happening. I didn't know who was to blame. I was very emotional, and I didn't trust myself to go and speak to someone who might not be at fault for any of this. So, I

declined to speak to him.

Q Okay, okay. I think you indicate in your statement that, a day or two later, the Cabinet Secretary for Health was also on the ward.

A Yes, Ms Jeane Freeman, yes.

Q And did you or your husband speak to her?

A She was in the doctor's room. We only knew she was there because we walked past to go to the toilet. No one was given the opportunity to speak to her. She was speaking to staff only.

Q Okay. We'll come back to think more about the communication around the move, Mrs King, but just, at this point, do you recall whether you received any formal communication about what was happening, in terms of a letter or something in writing?

A No. We've tried to remember. I don't think we did get a formal letter.

Q Okay. I’d like to think now about the immediate impact of the delayed move on your daughter's treatment, and I wonder if we could begin this chapter of your evidence by asking you to read paragraph 51 of your statement. Mr Russell, could we bring that up, please? (After a pause) Have you got paragraph 51 in front of you?

A I do.

Q I wonder if you could read that for us, please.

A

"We were just flattened by this delay and very, very scared. We'd planned this whole treatment plan around being told these new facilities were going to help manage the risks surrounding the treatment. The medical staff now had to try and manage this treatment in the old hospital with just a few days' notice. The isolation room that would normally be used for this treatment needed to be prepared. There was another child in there, who had to be moved out, so the room could be deep cleaned. Then I think the room had to sit for 24 or 48 hours after this deep clean, because they'd cleaned vents, they'd cleaned windows, they'd cleaned every single surface they could in this room. But it's just a pair of doors off the ward, right next to the playroom. Every single person walks past this door to get in and out the playroom. It really threw us, this idea that, we were already on this train of treatment, we couldn't stop, she had to keep going. And risks were now higher. It was a highly emotional period anyway. You know what you're doing to your child, you've been talked through at length, the risk this treatment gives her----"

(Witness upset)

Q Mrs King, I can finish reading that paragraph for you, if that would help.

"But if we didn't do this treatment, then she's going to die. The thought that this new hospital would help to manage those risks was a great feeling. We felt lucky that we were the ones who were going to get to go to this new hospital, and the staff were going to be able to do all these additional things to manage the risks to her. Being told, when the train is already in motion, that those facilities were not for us after all and that we were going to have to stay at the old hospital was a blow."

Are you okay, Mrs King? Would you like to take a break now or are you okay to carry on?

A No, let's carry on.

Q Okay, thank you. Does that paragraph sum up how you felt at the time?

A Yes, probably a few more expletives, but yes.

Q Yes. So, I take it from that paragraph and from what you've said that your fear was that, without the new facilities and the new hospital, particularly the isolation room facilities, that your daughter would be exposed to more risk, is that right?

A That's right, yes.

Q But as you’ve said, the treatment had started, and it had to keep going. There's no possibility of stopping and starting again at that point.

A (No audible reply)

Q So, what room was your daughter put in next?

A We got moved to room-- Well, she stayed in Bed 8, which is one of the beds on the open ward, until she was ready to move into the isolation room. And then the isolation room, they gave us Room 6 for that which is the one at the end that has the bathroom, en-suite.

Q You described that as the “high end” room.

A Yes.

Q Okay. To your knowledge, did that room have any type of specialist ventilation arrangement?

A We weren't allowed to open the windows during isolation because of the risk from outside. You also had the issue that – although they weren't meant to – parents regularly smoked in the bike shed next to it, and so the smoke would come through. Even with the windows shut, you'd smell it.

Q And aside from the increased risk that you've already described, did the delayed move of any direct impact on your daughter's treatment?

A I don't think we'd ever know.

Q Okay. You mentioned earlier that, at some point, you lost a day because of the chemo fridge being turned off----

A Yes. Yes.

Q -- but was that before or after the delayed move, can you recall?

A Maybe the day before.

Q I think you indicate in your statement that, at this time, you were extra vigilant about infection control.

A So, once she moved into isolation, that's when we became incredibly strict. So, before she moved into the room, we were given a grant from a charity to buy brand new toys and things for her to do. Those were already packaged in the room, waiting for her to arrive. We weren't meant to be taking anything particularly in with us apart from clothes and necessary-- But she was just turned six at that time, she needed her blanket and her toys, so we got some special disinfectant cleaning laundry detergent to try and clean things to take in with us. Every single item that we took in had to be wiped down with a disinfectant wipe and washed so it was clean when we went in.

We had a change of shoes at the door to the room, so we'd have a pair of flip flops for the room that could be cleaned easily, and then our outdoor shoes would be kept outside the room. Similarly, we'd keep-- My handbag, I'd keep my coat-- Anything that was an outdoor materials would be left outside the room so that, when we were going in and out the room, we would reduce the amount of infection that we're taking in with us.

There was a sign on the door saying "Infection Control, no entry" or something like that, and so the only staff that were allowed to go in were people who were medically needed to go into the staff. There was no auxiliaries popping in and out. There was no play specialist – there was none of that peripheral stuff allowed.

Staff, when they entered, had to wash their hands before they entered the room, and they had to put a pinny on – what you'd call PPE now. And if they had any form of cough, cold, whatever, they weren't coming in. If it was a doctor, they would put a mask on if they had that; they were more necessary than others.

Q Thank you Mrs King, I'd like to think now about the impact of the delay on the operation of the ward. We will come back to think, to reflect on the impact of it on you and your daughter, but just thinking now about the logistical operation of the ward: when you arrived on Ward 2 the day after the delay had been announced, what did you observe?

A At that point, they didn't know how long the delay was going to be for. So, they didn't know if they were repatriating everything back over to the old hospital or if they were just bringing what was needed for the next couple of weeks, and so they weren't sure-- And then, because the new hospital was clean and was ready to go, they also didn't want too much going backwards and forwards. So, we were told that some stuff was going to stay there until it opened, because they thought the delay was going to be quite a short one. As time wore on, they realised that this was a long delay, and so they'd start to bring things like obs machines over and other kit that had been bought brand new for the hospital.

Q I think you indicated before that, prior to the move, things were effectively running down.

A Yes, yes .

Q Were they now having to build it back up?

A Yes. Yes.

Q And again, were the nurses involved in that process as far as you could see?

A Yes, very much so, yes. Again, they had additional staff on shift to support that work.

Q You indicate in your statement that the playroom was affected by the delayed move----

A Yes.

Q -- is that right? What happened with that?

A The playroom was shut. They took all the toys out, all the DVDs out, removed all of the gaming machines, everything was gone. It had been shut up and taken to the new hospital, what could be taken, or they'd thrown out things that were old.

Q I think you mentioned the skip earlier on.

A Yes, there was a skip

outside, yes.

Q And was this eventually resolved?

A It took some time because, again, they weren't sure how long the delay was going to be. So, there was quite a few weeks of having nothing for the children to play with. I think, at this point, the play specialist was going round various charities to get support to get some more things back in for the children. It took quite some time to get that playroom back up.

Q And from what you observed, did the ward still function at this point?

A Medically, yes. Yes, it was functioning.

Q I think you're indicating that what little other facilities were there were affected by it.

A Yes. It was also taking some planning to know whether the next week was another week of delay or whether that was a week-- and which hospital were they going to be in, therefore how much equipment they needed in. For example, all the kind of chemo and such like has an expiry date on it, and they have to be kept in certain conditions, certain temperatures, certain light conditions, those kind of things need to be managed very carefully. So, you don't overbuy if you believe you're going to be moving to the next hospital because you can't move that with you; you only buy what is needed at that time. And it's incredibly expensive, this medicine, so they needed to manage that process carefully.

Q Okay, thank you in your statement, you say that you observed that the delayed move also had an impact on some of the staff in terms of their personal lives. Tell us about that.

A Oh, some people had moved house on the basis that they were moving. Some people had moved their childcare facilities. Some people had sold their car and bought an e-bike to allow them to do this move. They'd rearranged their lives to cope with a different location for working.

Q And again, from what you observed, did that have any impact on staff morale?

A You can't keep a nurse down; they're wonderfully positive people and will keep going. I mean, there'll be some whining, but they'll shake it off and carry on.

Q Okay, thank you. Now, at this stage – this is still in the very early days after the move – was there any indication at all about when the move might actually happen?

A Rumours again. They'd suggest "Oh, we don't know, it could be a few months", and then the more cynical one in the group would say, "Oh, it's going to be at least six months." Turns out they weren't cynical enough. You know, it was just rumours at that stage.

Q There was no formal line of communication at this point?

A No.

Q And at this stage, so again, in the fairly immediate aftermath, do you have any understanding at this time why the move had been delayed?

A No, just that it wasn't fit for purpose.

Q Thank you, Mrs King. I'm going to move on now to complete the chapter of evidence involving your daughter's treatment, and then we'll move on to reflect about some of these things. But you indicate that your daughter remained as an inpatient, I think, for a few more weeks. How did her treatment progress during that time? This would be the time she's having the high-dose chemotherapy.

A So, there was risks of complication to do with her liver, and we were told it would be about 40 percent chance. It turns out she did get this complication with her liver. So, that needed additional treatment. And then at that point, she got an infection – a really bad infection. We were told to expect that she would get temperatures, she would get chills, she would be feeling-- she would be vomiting constantly, she'd have diarrhoea; we knew that was all going to happen, but then she got the liver complication and the infection on top of that, and it floored her. She was incredibly unwell, quite scarily unwell at this stage. So, a lot of back and forth of trying to work out what this infection was.

She spiked a temperature overnight and her sats dropped – that is her oxygen saturation had dropped – and her heart rate had gone up. So, they put her onto O2 because it seemed the infection was in her lungs, she was crackling in her lungs. So, they were trying to work out-- I think she had ultrasounds, I think she had X-rays, but they couldn't work out what kind of an infection it was to know what treatment to give her. So, they went to broad spectrum antibiotics, but they weren't making any difference to this.

Over the next few days, they did a various number of tests. There was a lot of discussion as to whether they moved her up to HDU or whether they

keep her on the oncology ward. HDU would have been wonderful for the respiratory infection, but it might not have been able to manage the oncology treatment that she needed. And so, they decided that – if she stayed as she was – she was going to stay on oncology but, if her breathing got even, worse she was going to move to HDU. So, there was a lot of consultations back and forth as to how they thought she was doing, as to whether she needed to move at that stage.

In the end we had to take her off the ward to go and get this-- I can't remember what it was called, when they probed down into the lungs to take a sample of the fluid in her lungs. So, she had to get taken off the ward. My husband carried her with a mask on. He says he pretty much ran through the hospital to get her up there to get that sample taken. She had to be mildly sedated to do it. They didn't want to anesthetize her properly because they were worried that her sats were so low that she'd be in a coma, they wouldn't be able to bring her back 'round, and then she'd definitely be in ICU at that stage. So, they wanted just to do a light sedation to see if they could get this sample taken.

And I don't think they ever quite got to the bottom of what that infection was. I think they decided it was probably fungal, but had given her and antivirals, antibiotics and anti-fungicides (sic) to try and cope with this infection. Meanwhile, she also was needing regular blood transfusions and regular platelet transfusions because the chemo had knocked her immune system so low that there was-- It got to the point where you'd have a bag hung for her liver complication, you'd have a bag hung for infection. She only had two ports on her Hickman line. She also had a bag hung because she could no longer feed by tube, so she was getting TPN, which is nutrition through the veins rather than through the stomach. And they'd to work out the timing as to when they could give her a blood transfusion because that takes four hours, but you can't give a blood transfusion when you have a temperature – you have to wait to the temperature's steady. Meanwhile, while you're doing that, the platelets are running low, so you need to then work out if you can fit a platelet transfusion in between the next bag of treatment.

I think, yes, there was alarms going off constantly of each bag that was needing to be changed and flushed through, and the next flush coming on, and the next bag, and the next treatment. It was a revolving door of doctors and nurses coming in and out trying to get the right treatment for her at the right time.

Q Thank you, Mrs King. I think you indicate in your statement that your daughter did pick up after the infection event, and then, gradually through, I think, the autumn – so August through to October – she was in and out as a day patient, is that right?

A So, we were in high-dose chemo for seven weeks total. It was the entire school summer holidays she was in, and then she had a break treatment to help her recover but, because she'd had this liver complication, she was having to come in every single day for a one–hour transfusion, And then she was needing blood transfusions every couple of days, platelets every couple of days. So, yes, we were sleeping at home but coming back most days to hospital.

Q And am I right in thinking that the next stage of treatment was actually at the Western General Hospital for radiotherapy, is that right?

A That's right, yes.

Q Would you like to tell us

a bit about that?

A So, there was a plan. You can only do radiotherapy at the Western General in Edinburgh, you couldn't do it at the Sick Kids hospital. Had our first visit there, and we were given a person to be our kind of counterpart when we're there because it's quite a different set up for children because it's an adult hospital, with the odd child that comes and goes. And so, yes, we met the doctor, we met the staff, the radiologists that day to come up with a plan of how they were going to do this for her. They had to make her a mask, a horrible white mesh mask for her face, because she had to be pinned down to the table without moving and that’s how they did it. And she had to have a tiny dot of a tattoo on her abdomen so they could work out exactly where the radiotherapy was going to fire at her.

Q I think you indicate in your statement that they went to quite extraordinary lengths to make your daughter feel more comfortable or to reduce her fear about this process, is that right?

A Yes, they absolutely do the best. The mask, they painted up to look like a unicorn, even put a silver, sparkly horn on it. Each day they played hide and seek with the mask for

her, hid it in a different cupboard in the room, and she'd have to go and find it. We had a nurse with us for every single session that would be our counterpart who was there.

The actual radiotherapy is not nice for a child. She has to be in a room by herself, far away from everyone, so we'd had an audiobook that we had on the CD player in the room that she could listen to. And they got a rope, they put a rope on her ankle, and at the other end of the corridor I would hold the rope.

Q You mention in your statement they built a Lego model of the radiotherapy machine, is that right?

A Yes, they give you a Lego model so you can build that in advance, and you go for a tour in advance and go look at the machine before you go in. They talked her through trying to do some kind of meditative-- just to try and calm her down in advance, so they got her to close her eyes and think about nice things to get her through it.

Q Thank you. And after that stage of treatment, I think we move on to the next phase of this complex plan that she had, which I understand was immunotherapy; is that right?

A That’s right.

Q And when was it your daughter began immunotherapy?

A December. December 2019.

Q And was this back to the old Sick Kids hospital?

A Yes, we were back in Sick Kids, yes.

Q And what was the purpose of the immunotherapy?

A The immunotherapy is about teaching your body to identify the cancer. Essentially, there's a protein in the cancer that they're trying to teach the body to identify it and kill it, but also, when your immune system reacts, they start to know that there's cancer cells in your body. So, it's about mopping up what's left there, but also for the future – should you get a resurgence of cancer – potentially, this immunotherapy might reduce that growing.

Q And I think you mentioned that your daughter went through, I think, five rounds of immunotherapy?

A That's right, five rounds, yes.

Q And in the Spring of 2020, things became a bit more complicated because of the COVID-19 pandemic----

A Yes.

Q -- is that right?

A Yes.

Q But in May 2020, your daughter went into remission, is that right?

A That's right.

Q And she was discharged.

A As an inpatient, yes.

Q And I understand she then went into follow-up care, which would involve daycare appointments.

A That's right, yes.

Q And initially, was your daughter still attending the old Sick Kids hospital for these appointments?

A We did an awful lot of them by phone to begin with. We very rarely went in in person because of the COVID risk; maybe only once or twice. It was like a hard stop to treatment. Once she stopped being an inpatient, we barely went in again.

Q Then, I understand from your statement that you were moved over to the new Royal Hospital for Children and Young People in Edinburgh, is that right?

A That's right, yes.

Q Have you been to an appointment there?

A Yes.

Q How did you find out that's where you were to go?

A We got a leaflet, I think –

a letter telling us where to go, and a range of new phone numbers.

Q Do you recall when that was?

A I couldn't pinpoint it. I think after we had an appointment through the post but before we actually went.

Q Thank you. So, was that a direct communication about the opening of the new hospital rather than simply an appointment letter?

A No, the hospital had already opened but the cancer ward was the last one to move across, so we were still going to appointments in the old Sick Kids – almost empty hospital – whilst other people were now being treated at the new hospital.

Q Is that your understanding that, when eventually-- the last out the building----

A Mm-hmm.

Q -- so to speak, when the oncology ward moved, is that when you got a communication through the post to say----

A Yes.

Q -- "We've moved"?

A That's right, yes.

Q And what parts of the new hospital have you been to?

A Mostly to what's called "clinic", which is kind of an outpatient clinic area. But with my other daughter, she's had day surgery there, so we've been in that part of it as well.

Q What's your general impression of the new building?

A It's gorgeous. Gorgeous. It's bewildering, you can get lost quite easily, but it's clearly designed for children, so it's got pretty murals on the wall, and toys in every single waiting room we've been to. It's got a mini–MRI machine that you can put a teddy through and see pictures of it up on the screen. It's really well thought through. Space, so much space.

Q And did you get to experience the outdoor garden?

A No we haven't been up to-- well, my husband's been up to the ward cheekily, but I haven't been.

Q Thank you, Mrs King. There's just one more matter I'd like to cover off, and then I think it's likely that we'll have our morning break. So, this is really just before we move on to reflect on your experience, a couple of things you mention in your statement about water at the old hospital.

A Mm-hmm.

Q Now, you mention an incident where you understood that bacteria had been found in a treatment room tap, is that right?

A That's right, yes.

Q Could you tell us what happened?

A We got a letter handed to us by the staff nurse and she said, "Look, you can read the letter, but basically they found some bacteria in that tap. That tap's been closed off. We won't be using that tap" and that it's getting looked after. It was her or someone else that told us this is the same bacteria they'd found in the water in Glasgow, so they were taking it very seriously.

Q But it was communicated to you, what had happened, by a nurse and in writing, is that right?

A Yes, that's right. Yes.

Q How did you feel about that?

A It was a tap that wasn't particularly used to be honest. It wasn't the main one, and it was only one tap in the whole ward, so I wasn't particularly worried, no.

Q And did the fact that you'd been told what was happening help reassure you that it was being dealt with?

A Yes.

Q You also mention a time where some of the nurses from the Glasgow hospital had come over to the Edinburgh hospital, is that right?

A That's right, yes. Some of their staff had come over as additional staff members. I believe their ward had been shut, so they'd moved across.

Q Okay. And I think you recall some of the Edinburgh-based nurses making some observations about the approach of the Glasgow nurses to water in the hospital; could you tell us about that?

A They said it's like they had PTSD; they were scared to wash their hands in the sinks that we were using. They were concerned that we were washing our hands just with tap water and soap, and that they used bottled water in Glasgow to wash their hands. They didn't use the tap water at all. They said it was it was quite a strange procedure that you have the Edinburgh nurses working side by side with Glasgow nurses who had a completely different approach to how you deal with water.

Q And I think you've said there that the Edinburgh nurses felt as though the Glasgow nurses had "PTSD".

A Yes, that's what they said. Yes.

MS ARNOTT: Thank you, Mrs King. My Lord, I'm conscious that's half-past 11 and I've come to a natural break in my questions for Mrs King.

THE CHAIR: Yes, we'll take a break. As I said, we usually take a break at about half-past 11, Mrs King. 20 minutes, if that suits? So, if Mrs King can be shown out.

11:30

(A short break)

11:50

THE CHAIR: Ms Arnott.

MS ARNOTT: Thank you, my Lord. Mrs King, we are now moving towards the conclusion of your evidence. And what I'd like to do now it move on to ask you to reflect on certain parts of the experience that you've described this morning. I'd like to start by asking you about your reflections about the old Sick Kids as a hospital facility generally. I wonder if you could tell us-- From what you've described, I think you indicate that you felt there was a gap between the high level of care that was provided to your daughter by staff at the hospital and suitability of the hospital as a place to provide that care. Would that be right?

A Yes. I think the building let them down. I think they were amazing at what they could do, but they were limited by what they could do by the facilities that they were in. It impacted on the level of care they could possibly give, I think.

Q How would you asses the old hospital building as a facility to provide your daughter with treatment?

A Difficult to navigate in. It was a warren of a building of many different extensions put on at various points as when the need was there. So, you could be in a modern part of the hospital and be in big wide rooms and spacious and easy to care, and then you'd be in the older, darker, harder bit of the hospital to be in. But my grandpa worked in that hospital; that's how old it is.

Q Thank, Mrs King. You indicate, and you don't need to look at the bit, it's around about paragraphs 74 and 75 of your statement, of some specific aspects about the hospital building which, in your view, detracted from the provision of good care. I wonder if you could take us through those. Please have a look at your statement; it's paragraphs 74 and 75.

A Yes. I mean, this actually is going back to a part that I did hope that we could talk about, was toileting facilities. So, her immunotherapy period we've skipped over a bit but Lily caught C. diff. during her first round of immunotherapy, which meant she was put in isolation again. A risk to the other children in the hospital. She had uncontrollable diarrhoea that was awful, and we couldn't get a toilet. She was in a cubicle with no toilet. She was losing function constantly.

I was having to drive around Edinburgh late at night to find a supermarket open to buy pyjama bottoms for her because by the time it would take me to run upstairs, put washing in the washing machine and get back downstairs again, she'd have lost control again. I think we had about 30 pairs of pyjamas with us at one point. And she was going in a potty. She was six years olds, which I think was just degrading, and terrible for a child to have--

She didn't mind because she's six years old and she doesn't see, but all the visitors to the ward, every time she needed to go to the toilet, she would just drop her trousers and go. There was windows on the front of her cubicle, so the Edinburgh Rugby Team has seen my child going into a toilet. Celtic Football Team has seen her. So many people have seen her because she had uncontrollable diarrhoea and there was no toilet facilities, there was no privacy for her to (inaudible).

Q And I think you've just indicated that while your daughter had C. diff., she was in a room with no toilet facilities at all?

A That's right. She was in Cubicle 1. So, that's the busiest room at the top end of the corridor, opposite the daycare beds, and no toilet.

Q Thank you very much. I think you've indicated in your statement there were some other aspects of the building that you felt impacted upon care. What about the infection control on the ward? I think there were some issues, you indicate, in relation to plaster coming off the walls and that kind of thing that caused you concern about infection control.

A I don't know if that was necessarily on the ward, but certainly in the corridors in and around the hospital, yes. There was patchiness in terms of the structure of the building was coming apart.

Q And was there frequent maintenance to deal with that?

A Oh, maintenance around every single day. They'd be patching up a hole in a wall, they'd be patching something in a ceiling, they'd be patching a pipe, fixing the plumbing. Yes. Maintenance around constantly.

Q That was a regular feature of your experience at the hospital?

A Oh, yes. Yes.

Q And I think you indicated earlier on in your evidence that one of the issues on the ward that you experienced was the tight size of the rooms----

A Yes.

Q -- and that I think you indicate that, in your view, that hindered care to some extent.

A It made it difficult to be able to give her personal care as well as medical care at the same time. So, if you needed to get an ultrasound machine into the room – which we did very regularly to check things over – you would have to remove all the chairs and furniture out of the room to allow the ultrasound machine in. If she wanted to hold my hand because she was scared during it, I had to climb over the bed and sit on the windowsill to hold her hand while she's getting an ultrasound or an x-ray.

If you then wanted a doctor to come in and check her over at the same time as a nurse is trying to hang chemo, again, us parents would either have to leave room or stand on a bed or something like that. It was a complicated game of chess every time you needed to get in and out the room with (inaudible).

Q I think you indicate in your statement that all of these things together, you felt, let the staff down, is that right?

A I mean, they're stellar. They can cope with absolutely anything, but yes, if they had the space and the facilities to do things, they'd do an even better job than they do. Whether it would have affected her outcome, I don't know, but it affected mentally, physically, access, yes. It was difficult in that hospital.

Q How would you assess the old building in terms of its facilities that it could offer a family attending hospital?

A It wasn't designed for families. It was designed for the child to get treatment. It wasn't designed for the families to be with the child. It was designed at a time when children were dropped off at hospital and picked up when they were better. It wasn't designed for parents to be with their child and give them that emotional care and support, which we now know is a really important part of a child getting treatment, and actually supports their successful outcome if they have family and friends around them to give them that care and support. They've had add-ons to the hospital from charities that have tried to cope with some of that, but the reality is the hospital was not designed for families, it was designed for the child.

Q Thank you, Mrs King. I'd like to move on now to ask you to reflect again about the communication around the delayed move. How would you assess the communication about the delay?

A Word of mouth, rumours. Nothing official. In fact, the most I would read would be in the newspapers, and that's where I went to get any form of information, because the staff didn't know anything officially.

Q And I think you indicate in your statement that, in fact, you found out a bit more from the press about the reasons for the delayed move than you had found out within the hospital, is that right?

A Oh yes.

Q What did you find out?

A From the newspapers, it seems that where the flaws in the building were particularly focused around the oncology department, and particularly focused around the room she was going to move to.

Q So, that's about the isolation room facilities?

A Yes. The ventilation was

insufficient. It wasn't to the spec that it was meant to have been at.

Q And did you ever receive any communication from the hospital management or form the Health Board about the delayed move?

A Don't believe we did. We've kept all the medical papers, we haven't kept other things, but we don't believe we got a letter.

Q And I think you indicated earlier today that there was one opportunity to speak with the Chief Executive the day immediately after the delay, but beyond that, was there anything else offered?

A No. No, nothing.

Q Are you aware of any communication from the Scottish Government about the delayed move?

A No. Not aware of anything.

Q But you indicate in your statement that you saw the Health Secretary on the news at one point?

A Yes. I saw them giving statements to the news. I saw them talking about the building, the hospital, and I got very frustrated with that because they didn't seem to be talking about the children and the effect on their healthcare as a result of this. It seemed to be an awful lot of pointing of fingers, of someone is at fault, but no consideration to the impact on people.

Q So, your impression, then, was that the discussion that you saw on the television, and I think you mention in your statement, in Parliament related to the hospital building itself and where fault lay for the delay.

A Yes. Yes. Around the building and the contractors and the NHS and the Health Secretary as to who was at fault for a building not being opened.

Q You felt there was a crucial piece of that puzzle missing?

A Exactly. The children. There was no consideration of the effect this is having on children. And we seem to be talking at length about the risks the new hospital was going to pose to children, but there was no consideration of the existing hospital that they were in and the condition of that hospital and how that affects treatment.

Q Was there ever any communication, when you were back at the old hospital after the move had been delayed, with you about how they were going to manage those risks or what they were going to do until the new hospital opened?

A Because her treatment had already started, the high-dose chemo, there was no changing things. So, her oncologist said, “Look, we’ll manage it like we’ve managed every other child in this process. We’ll continue as we have done. Not to worry, they’ve got this. They’ll get her through this.”

Q And were you kept up to date at all with progress on when the new building might open?

A It was generally a by-the-by. You’d have a meeting about a treatment plan or something, and someone would off the cuff at the end say, “Oh, what about the new hospital?” “Oh, ignore that. It’s not going to happen.” Or, “Maybe next month. Maybe in six months.” And as it turned out, it was after treatment had ended.

Q And there was no formal communication with you about that?

A We don’t believe we’ve ever had anything.

Q Not until the ward eventually closed?

A Not until it actually moved. Yes.

Q Okay. Mrs King, I’d like to ask you to read another paragraph from your statement, if that’s okay? Mr Russell, could we bring up paragraph 81, please? Mrs King, this paragraph deals with how you felt about the communication overall about the delayed move. Do you have that in front of you?

A Yes.

Q I wonder if you could read that for us, please?

A

"I don't think that the way the hospital or Health Board handled the delay or the communication of this was great. I appreciate that a last minute decision was taken to delay the move and it was take for a good reason. The staff were communicated with, but the parents were not communicated with. We got the trickle-down effect from the medical staff. We did have a wonderful nurse on our ward who kept us parents informed, but she could only inform us of what she knew. And then, after that first initial communication from her, it was all hearsay, which is not ideal. It's almost as if management think that because the patients in the children's hospital are children, they don't need to communicate with them. The reality is, behind all those children are parents and guardians who they can communicate with that they don't communicate with terribly well."

Q Thank you, Mrs King. Thank you, Mr Russell, that can come

down. Does that sum up how you feel about the communication around the move?

A Very much so. Yes.

Q Yes. Mrs King, I'd like to move on now to think about the impact of the delayed move on your daughter and on your family. Now, you've already given us quite a lot of evidence on that today, so I'm going to ask you about your overall reflections on it. How would you assess the impact of the delayed move on your daughter's experience at the hospital?

A It greatly upset her at the time. She'd been promised a ride in an ambulance, and when you're a child on intensive treatment, you get a series of beads; a special bead for each bit of treatment you get. And she was very much looking forward to going in an ambulance and getting the beads that showed that she was getting it. She'd also been promised that this new hospital was going to give her an awful lot of freedoms and more fun than she was currently having.

And so, she was really, really upset. She was crying a lot. It affected her emotionally at the time. I think long-term it probably hasn't affected her because she was quite young. Although, she is going through therapy at the moment to try and deal with treatment, trying to process some of the things. She does ask me questions about the hospital, almost to remind herself what the hospital looked like and how it functioned. But yes, it affected her emotionally, definitely at the time; long-term, I'm not sure.

Q I think you indicate in your statement that it was like a new toy that had been waved at her and then taken away.

A Exactly that.

Q And that it had been a positive point of focus for her during her treatment.

A Yes. Trying to find a high point when you're going through cancer treatment at that age is-- There's not many out there. You're not allowed to travel more than an hour from home, you've spent your whole time in hospital having a rubbish experience, frankly, and so being told she was going to go to this new, exciting place that was purpose built with her in mind, that was going to have these wonderful facilities for her, and she was going to enjoy yourself, and then to be told it's just not happening. Yes, it crushed her.

Q Thank you, Mrs King. I'd like to ask now how you would assess

the impact of the delayed move on you and your family in terms of the experience that you had.

A It scared us. It scared us massively. We were already facing a really scary period that we knew was a huge amount of risk involved in it, and then to be found that this purpose-built facility was not going to be available for the treatment was terrifying, frankly. Terrifying.

Knowing what we knew about the hospital, they'd do the best they could with it, but it wasn't the best place to be getting this treatment. We were very lucky to live on the doorstep of the Scottish Centre for Cancer Treatment for Children. We had the best doctors and staff there. We didn't have the best facilities, but we were meant to be getting those facilities. So yes, it was scary to go through that.

Q Thank you, Mrs King. I think in your statement you indicate that, to some extent, those feelings were mixed with a sense of relief when you found out why the delay had actually happened, is that right?

A Oh, once we found out-- So, I'd gone from being very angry that we hadn't moved to being incredibly relieved that we hadn't moved. They'd discovered that the flaws were as significant as they sounded; that what looked like a brand-new, fancy facility was not what it seemed to be, and that it was very much centered around the room we were going to be in. We were very relieved that we hadn't moved.

Q And does that come back to what you mentioned earlier about the balance of risk? You had the balance of risk of your daughter being in the old hospital facility against this potential risk of being in the new hospital facility with the problem with the ventilation?

A Exactly. And it's conflated with-- We knew that Glasgow, at this point, had been hit in the press. The Glasgow Hospital, it turns out not only increased risks, it, in all probability, contributed to the deaths of children. Children like ours. And to discover it was the same contractor behind this, was ventilation the only problem there? We didn't know at that point how many flaws there were behind this hospital, who had been managing this process to check. But if you have the same contractor on two hospitals, two hospitals that have flaws on a similar basis, this was really quite worrying, then, to know that we'd just missed a bullet, frankly, is what it felt like.

Q Thank you, Mrs King. After all of this happened, do you form a view about Health Board's ability to deliver a project like this?

A I have NHS staff in my family who have been involved in some of these planning side of things, and my concern was perhaps the wrong people were managing a project. A building project to me should have a contractor that understands project management of a building, not project management of a health care system, and from what I was reading, it sounded like the wrong people were in charge of the management of this project.

Q Thank you, Mrs King. You talk some more about that at paragraphs 89 and 90 of your statement, and I'd like to ask you to read those, if that's okay? Mr Russell, could we please bring up paragraphs 89 and 90? Mrs King, could I ask you to begin by reading paragraph 89, please?

A Yes.

> "By not having a hospital move, it caused a lot of emotional upheaval and concern for parents, patients and their families that was unnecessary. There'd already been a very long build as it was. There had

already been a previous delay from when it originally meant to open, and then the move was cancelled at the last minute. Surely the number of checks that have been done to that point meant they should have been able to catch any issues and reduce the impact that we were dealing with later.

If the Health Board had contracted someone who is an expert in building hospitals, then you'd expect them to understand the necessary requirements for building a hospital. It turns out that these contractors are behind two hospitals with major flaws. Equally, the Health Board only builds a hospital once every 50 years. So, how much experience do they have within a Health Board for this kind of project? It seems to be a classic case of public sector organisations trying to project manage on something they don't have much experience in. There must be lessons to be learned."

Q Thank you, Mrs King. Mrs King, I don't have any more questions for you, but before we conclude, is there anything you would like to say or to add that we've not

already covered this morning?

A I suppose my testimony would be to the staff. I think I've mentioned them time and again but they gave my child back to me (witness upset).

Q Please, take your time.

A Cancer treatment is (inaudible). They cured her, and that's down to them. And I don't want to have-- I want them to be known. They did absolutely everything they possibly could to support us during this, as much as they could, and if they were let down, it wasn't down to their fault, it was down to someone behind them. Medically, there were no flaws in what was done. The flaws were administrative and management above that level. Yes.

Q Okay. Thank you, Mrs King. My Lord, I don't have any further questions for Mrs King.

THE CHAIR: Thank you, Ms Arnott. Thank you very much, Mrs King. Thank you for coming and giving your evidence in person. Thank you also for providing what's a full and useful witness statement. Both are part of the evidence that you've contributed to the Inquiry and both will be considered as part of all the evidence before us. But thank you very much, and you're now free to go.

(The witness withdrew)

THE CHAIR: Now, I understand the timetable is we have a witness for two o'clock this afternoon.

MS ARNOTT: That's correct, my Lord.

THE CHAIR: Right. We'll adjourn until two this afternoon.

12:15

(End of Morning Session)