Scottish Hospitals Inquiry

Witness Statement of

Lesley King

WITNESS DETAILS

1. My name is Lesley King. I was born on [redacted]. I am [redacted] years old. I work in [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted] . She is 8 years old.

3. I live with my husband, [redacted] and our two children, [redacted] and [redacted] in [redacted], [redacted].

OVERVIEW

4. My daughter is [redacted]. [redacted] was diagnosed with neuroblastoma in October 2018 when she was 5 years old. [redacted] was treated in the Royal Hospital for Sick Children ("RHSC") in Edinburgh between October 2018 and May 2020 when she finished her treatment. She attended as both an inpatient and an outpatient between those dates. [redacted] continued to attend at the RHSC for check-ups until it shut in March 2021 and now attends at the new Royal Hospital for Children and Young People ("RHCYP").

5. [redacted] spent the majority of her time in ward 2 (haematology and oncology) of the RHSC and also had brief stays in ward 3 (speciality surgery), ward 4 (orthopaedics) and the Intensive Care Unit (ICU). My husband and I stayed with [redacted] throughout her admissions as an inpatient and outpatient and I can speak to the experience that [redacted] and I had on these wards.

6. There are some specific events that I would like to mention. I have some observations about the condition of the hospital building in the RHSC and the impact that had on our experience there. I also have some observations to make about the way in which the delay to the opening of the new RHCYP

in July 2019 impacted on us. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my husband [redacted] and our two children in [redacted]. [redacted] is the eldest and [redacted] is [redacted].

8. [redacted] is a very busy little girl. She loves the outdoors and playing on her bike and her roller skates. She loves going to the local park and we have two dogs, [redacted] so we are out often walking them. She has loads of hobbies and does bouldering, hillwalking and kayaking. She gets on well with [redacted] and they have a lovely relationship.

9. As a family we are very active and the kids have been roped into the adventures of me and my husband. We live in the countryside so we have lots of opportunities here. We hill walk and cycle together and we have kayaks and paddleboards, so we are always going out to explore.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE RHSC IN EDINBURGH

Admission to hospital: 3 October 2018

10. [redacted] was diagnosed with neuroblastoma, which is a childhood cancer, in October 2018. In the run up to this diagnosis, [redacted] had had a sore tummy and was repeatedly sent home from school. There were a couple of times she was up during the night in agony and Calpol didn't seem to make any difference. We went to our GP who couldn't find anything wrong but had taken a urine sample. A few days later we were asked to go back to the GP as there was something funny with the urine sample, but they put it down to a virus in her adrenal glands. They did tell us that if it got worse that we should go to A&E. They didn't believe it was appendicitis but suggested

further tests may be necessary which could only be done in hospital. [redacted] got a lot worse and my husband took her to the GP who sent her straight to A&E.

11. We took her to A&E at the RHSC on 2 October 2018. They did an ultrasound and found a mass on her kidney. We got sent home and were told to come back the following day and go to the oncology department, which we did. This is where we met all of [redacted]'s doctors for the first time. Her consultant was, and still is, Dr Angela Jesudason. The doctors told us that from the ultrasound, and from looking at [redacted], they could see that she had lumps in her neck, that one of her eyes we dilated and the other eye was closing. They were certain that she had cancer and needed treatment. [redacted] did not want them touching her as she felt awful, but they took a blood sample and sent us home. A couple of hours later they phoned us and told us to return immediately as the blood tests were troubling and suggested that some of her organs might be failing. When we returned, a second blood sample was taken and she was admitted to ward 2 which was the oncology/haematology ward. I think she was in hospital for nearly a month that time as she was so sick.

Description of Ward 2

12. [redacted] stayed in ward 2 95 percent of the time she was in hospital. Ward 2 was the haematology and oncology ward in the RHSC. The hospital is a big Victorian building and ward 2 was essentially one big long corridor and was like an old-fashioned nightingale ward. One side had been portioned off so that there were cubicles with glass fronts on them. There were six of these cubicles which have doors on them. There are two beds in the main area of the ward which were for overnight stays and just have curtains round them. Then there were four day-care beds in the same space. They did have curtains but I don't think they were ever pulled round.

13. The cubicles had a door that you could shut for privacy and there was a glass front with blinds that you could shut. They had windows directly out

onto the main courtyard of the hospital which was the car park. The rooms varied in terms of quality. Room 6 was the “high-end” one that everyone wanted, because it had its own toilet and bath and it had space to move around in the room. Room 5 had a toilet and washbasin and it had no window to the outside world, so you had the positive of getting a toilet, but then you got no daylight at all. And then, Room 1 was a big room, no toilet, but it was right next to the treatment room so it got very, very noisy, with all the nurses getting all the treatment together. Then there were the rooms in with middle which were fine but had no toilet. Some of the rooms in winter were absolutely freezing cold, to the point where we sellotaped the window shut, to stop the wind coming in. But equally in summer, they could be utterly roasting, because you'd get the sun coming in. We used to try and get the best cubicle depending on what time of year it was.

14. There were two treatment rooms on the ward. Treatment rooms are where they put together the chemo bags and syringes. They are also where they draw blood from children and do the minor procedures that they can't do in the rooms. At the time we were there, because day-care and the ward were in the same place, they were very busy with day-care patients coming and going. Some of the kids, usually the ones with leukaemia, tended to get their chemo as day-care patients. There were other kids who were maybe in for other procedures, or having an operation, who would be in the day-care beds.

15. Only two of the cubicles had en-suite facilities, so there were two toilets on the wards for the children. There was additionally a bathroom for the children to use. They were at the furthest end of the corridor. There were also two commodes. The trouble with the commodes is that, in most of the cubicle rooms, the commode didn’t fit fully into the room so it was difficult for a parent to help a child onto the commode with the door shut and get any kind of privacy. If the child was attached to a drip stand, which they generally were, then you only had so much reach to get onto the commode. We tended to find that, at night, because of the treatment when they were flushing out the chemo, [redacted] would need to go to the toilet in a hurry and there

was rarely time to get up the corridor to the bathroom or go and get the commode. We ended up bringing a potty from home. [redacted] was young enough that she didn't mind doing that.

16. There was no toilet on the ward for parents. For infection risk, the nurses wanted parents to go elsewhere so we had to go off the ward and find a public toilet to use, which was in another part of the hospital building. If we wanted to have a shower, then we could use PJ's Loft which was an area for parents which was run by the Sick Kids Charity. It was at the very top of the building. It wasn't ideal as it was a five storey climb up the stairs and it could take half an hour to go and get a shower and then come back. There was a kitchen and a small launderette in PJ's loft, so you could go and wash clothes. There was a little sitting room, showers and bathrooms up there. There were also bedrooms, but we never actually stayed in one of the bedrooms. They were for people who were coming from a long way away. The PJ's loft facility was falling apart by the time we were using it, and it continued to fall apart. For example, there would be one shower that would work, and you had to get out of bed early to try and make sure you got that shower. The windows were rotten and couldn't shut in some of the rooms. It wasn't great, but it was somewhere useful for us to go to and we used it every morning when we were staying overnight.

17. [redacted] was an inpatient for most of her treatment so we would be with her 24 hours a day. We were part of the care she needed. I mean, there were some parents that didn't stay, but [redacted] needed additional care from us for the toilet, for cleaning herself, and for entertaining her. There was a fold-down bed for parents in every single cubicle, that you pulled down late at night. It was a comfortable camp bed. There wasn't much room once they were down. There would be two chairs during the daytime, in each cubicle, and at night time, to pull the parent bed out, you had to take the chairs out into the corridor and leave them there so you could pull the bed down at night.

18. In terms of facilities to keep the kids entertained, there was a playroom at the end of the corridor. It was quite a nice, bright room and it had TVs,

PlayStations, things like that. There was big, big bank of DVDs that the kids could take back to their room if they wanted. There were some books, colouring and drawing materials, jigsaws, toys, games. Sometimes you'd have the play specialist come in and they'd do some kind of organised fun for the kids in the playroom or out in the corridor. The play specialist would also come round the rooms each day and give the kids who couldn't make it to the playroom something to do. The staff on the ward let siblings come in and use it too as they felt it was really important that patients could still have interaction with their siblings, especially children like [redacted], who would be spending a long time in hospital. Sometimes parents are in there for a long time, so actually having a playroom where the "non-sick" child could go and have a play that was safe, was really handy. There was also an area for the Teenage Cancer Trust, but I didn't use this at all as it was for older kids.

19. There weren't any facilities on the ward for parents to use. There was a kitchen, but there were strict rules that parents weren't allowed into the kitchen. We would have to go and ask for one of the nurses to store our food in the fridge. We would have to go and ask one of the nurses to heat our food up for us. We were allowed two cups of tea a day, one first thing in the morning, and one at night, if the auxiliaries remembered, and had time. But otherwise, parents were expected to go out, off the ward, for anything they needed. If we wanted we could use PJs loft, but it was not easy to access. There was the shop, which was close to Ward 2, so you could get sandwiches, drinks and bits and bobs for children. It also had shampoo, and such like, if you'd forgotten anything. Although our ward was wonderful and they always had a supply of things to give you if you'd had an emergency and didn't have anything with you. There was the canteen which I only used it a few times, just because it was a bit awkward to get to. There was also a WRVS shop, down at outpatients, that you could go and get a cup of tea from, and a scone. When the hospital didn't move, they shut it just before and never reopened it for quite a long time.

20. On the ward itself there were a lot of staff. Maybe five or six doctors, from junior doctors to registrars to consultant level. On the nursing staff, I think

ten or more nurses. There were also a number of auxiliaries, student nurses, cleaners, the play specialist and the ward admin lady. I think the nursing/patient ratio was almost one to one and each morning you would be told who your nurse was for that day.

21. The nurses were the most amazing group. We had alarm buzzers in our room, and depending on how urgent your issue was, this determined which buzzer you pressed. There was an emergency buzzer which would mean all staff in the vicinity would drop everything and run. Or there was a standard normal alert button we used if the chemo bag had run out, or we needed help cleaning up a soiled child. Generally, someone would very quickly come along to see you if you pressed the normal buzzer. Some of the nurses were spectacular, in that in their head, they could almost count down to the minute as to when your drip was going to run out and they could get to the room in time to swap over for the next one. It was impressive to watch actually, because it takes a lot of time and effort to put together a chemo bag. For them to be able to coordinate all the children on the ward to be able to get their chemo at a time that allowed them to get their full schedule in, and get them home again, was impressive. The nurses cared, a huge amount.

22. Some of the nurses were trained in how to give chemo. Chemo is really regulated as to how they're able to give it. So, every time that it's given, somebody else has to be in the room to check that the nurse has done their calculations correctly, that they've set the pump correctly and they've signed off the associated paperwork for the chemo. There's a whole pile of student nurses who were pretty much only allowed to carry pee, poo, and a bottle of juice for a child, I mean, there was nothing, really, the student nurses were allowed to do on this ward except observations (temperature, O2 saturation, blood pressure etc.), because it was so specialised.

23. During daylight hours, there would generally always be about two or three doctors on the ward, as a minimum. First thing in the morning when the ward rounds took place, you get far more doctors around at that stage,

maybe four or five at that time. As the day progressed it would be down to about two or three. Overnight, there wouldn't be a doctor on the ward, but there'd be a doctor on call in the hospital, so that they would be called in should something be needed. However, almost every single time we'd get a doctor from the hospital on call pulled in, we'd end up getting a consultant coming from home to come in and help out.

[redacted]'s initial treatment: October 2018

24. When [redacted] was admitted we were told she had cancer, and the doctors just needed to work out what type it was so they would be able to create a treatment plan. She had all sorts of tests at that stage: an MRI, a CT scan, a bone marrow sample. She was anaesthetised for those procedures. They also tried to put a Hickman line in her chest, but the position of the tumours meant that wasn't possible, so they put a femoral line in at the top of her thigh. She was anaesthetised for this too and it was essentially a long tube that goes inside the artery, which has a cap on the end so you can administer medicines, including chemo, down directly down that line. I think [redacted]'s had a double tap on it, so that she could receive chemo, but blood draws could also be taken at the same time. These lines have to be changed every seven to ten days so the challenge with that is, they had to keep anaesthetising [redacted] every time a new one needed placing. I think [redacted] had to go through seven rounds of chemo before the tumours had shrunk sufficiently to place the Hickman line.

25. [redacted] was in for four weeks during this first admission. In the first few days she was having tests to establish what type of cancer she had and she also had to have blood transfusions as her blood was basically water and her heart was struggling to cope. Once they had diagnosed Stage 4 High Risk Neuroblastoma, a treatment plan was established. Neuroblastoma is a childhood cancer, so you rarely get such a thing in adults. Essentially, at some point, one cell has divided wrong, and has carried on going. It's not genetic; it's not related to any kind of environmental cause. It starts around the neural lines, so it tends to happen around the kidney, and then will go

up the spine. [redacted] was stage four. She had a huge mass in her stomach, around her kidney, and around her spine. It had spread across to the other kidney as well. It was running up her spine, and there were several tumours around her neck, that were quite significant. It was also in her bone marrow space. So it wasn't the bone marrow that was infected, it was actually growing within her bones, and was taking space from the bone marrow. That was why she was at the point where she had nothing in her blood, because there was no bone marrow to grow red cells, or white cells, or anything like that. This is why she required multiple blood transfusions. Essentially, she had no real bone marrow from around her jaw, to below her pelvis; that whole space of her body had just become cancerous. So when you saw the scans, her skeleton looked black, from the jawline to below the pelvis.

26. At that stage we were told the standard protocol for Stage 4 High Risk Neuroblastoma. We were told it was going to be a nine-month treatment plan, all going well. There would be eight rounds of chemo called rapid COJEC. That would be followed by surgery. Then there would be high dose chemo with stem cell rescue. That would be followed by radiotherapy, and then there would be immunotherapy. [redacted] would get scans after four rounds of chemo, and then again at eight rounds of chemo, for the doctors to work out what kind of progress they had made in shrinking the tumours.

27. Her chemo started a few days after she was diagnosed. She had to be treated as an inpatient as she was considered too high risk to go home at that stage. Her blood was so thin that her heart was at risk of giving out. She was also at high risk of infection and had no immune system. I think we had about two weeks in Room 1, and then another little boy who was incredibly sick needed that room, so we got moved along to another room. Room 1 tended to be used for children who were quite ill and needed to be observed closely. It was right next to the treatment room, so it was in full view of the nurses, all the time.

28. [redacted] was getting chemo every ten days, although it took five days to administer the chemo. She would have an infusion that lasted for 24 hours, for five days, then have a few days off, and then start the next one. I think she had three or four rounds of chemo in that first admission. She was also getting blood transfusions during this period and she was getting antibiotics. After a couple of weeks, she also had an NG feeding tube inserted into her nose down into her stomach as she was having trouble with eating. She had lost so much weight before being diagnosed. She was really sick with the chemo and even on the feeding tube we could only administer small amounts as she was being sick so often. She was on a lot of antiemetics to stop her from being so sick all the time. She was pretty much flat on her back in bed during this period and we had to get the physio in to look at her and stop her muscles from wasting.

Treatment between October and January 2019

29. Despite how ill she had been, after four weeks of treatment, the doctors considered that [redacted] was stable enough to be discharged and she was allowed home. She was back in ward 2 again about three days after being discharged. Because she was on a ten-day cycle of chemo, that meant we were in hospital for five days, home for a few days, back in for five days. We were also under strict instructions that if [redacted] got a temperature of 38 degrees or more, she had to return to hospital for 48 hours. So we were never far away. On the days when we were officially at home, we would be in for day-care for line care, or an infusion of some sort, or a check-up, or something. I think we only had something like 24 hours away from hospital at any one time. I think of the eight rounds of chemo, there was one where we were allowed to do it as day-care, only. But this meant we were in day-care for ten o'clock in the morning, and left at five at night and this would continue for the whole round of chemo.

30. During this time, [redacted] had multiple blood transfusions, platelet transfusions, and was getting fluids constantly. She had three surgeries to get her femoral lines changed. She was having biopsies taken from her pelvic bones, so

she needed to be anesthetised for that too. She also got her Hickman line in during that period, on 8 November 2018. She had to go into ward 3 for a night for this to be done and it was a terrible experience.

31. Ward 3 was a surgical ward but was like a factory of children having operations. It was a dormitory style ward. There was maybe a metre and a half between beds and just enough room for a bed and a chair for a parent, and then there'd be another bed and a chair. There were children in getting their tonsils out or having other minor surgeries, and then you'd have the odd child, like [redacted], who needed additional care. There's just bed after bed full of screaming children, and worried parents. It is noisy and there are lights on all the time. They did let parents stay overnight, but they only had enough space for parent beds next to some of the beds. I wasn't allowed to sleep next to [redacted] and I had to sleep on a parent bed in the playroom at the end of the corridor, with another four or five parents. I kept coming back and forth to see [redacted] and I would sit on the chair with her for a bit. She woke up at a point when I wasn't there, and got very scared and worried, because she'd just had an operation and was feeling awful. Someone helped her to the toilet, at which point she was sick, and she soiled herself and the nurses had to help her out. Then she spiked a temperature and got moved into a cubicle, which I didn't know. I walked back to her bed and couldn't find her, and got very scared. There were three cubicles on the ward which were meant for children who had severe burns and had infection control issues. [redacted], as an oncology patient, when she spiked a temperature, trumped other children in terms of infection risk, and she got moved into a cubicle and they got moved out.

32. There was no obvious infection control protocol for [redacted] as an oncology patient. There were far fewer nurses per patient, compared to what we were used to, and the amount of space they had to move around. On top of that, the behaviour of the parents was different. In ward 2 every parent there knows that the risk of infection is incredibly high so they behave in a certain way that is respectful of others around them. Whereas, in ward 3 it was like being at a public shopping centre, to be honest. There would be

umpteen siblings who'd be running up and down screaming, touching things, moving things, and people coughing on you. It was unpleasantly scary. I'm sure the doctors washed their hands before they came in, and I'm sure the nurses were washing their hands, but that was just one layer of all the various things going on in that space. Luckily, [redacted] returned to Ward 2 the following day, to start chemo.

33. Once [redacted] finished her chemo in December 2018 there was a bit of a pause in her treatment. Around Christmas she had a really bad staph infection that had to be treated with antibiotics and then the doctors were discussing what to do next with [redacted]. The oncologists wanted to do surgery, but the surgical team thought it was too risky. The tumours around her kidney were wrapped around blood vessels, and they were concerned that if they were to do it, she would be at high risk of bleeding out on the table. There was a lot of back and forth talking to the team in London, at Great Ormond Street and even discussions of [redacted] going to America for surgery. So we had a few weeks of not very much happening. We'd get a scan, we'd have a pause, we'd get a scan, we'd have a pause. I think it was about three weeks of nothing, which was quite scary, when there had been such intense treatment and then have no apparent plan.

[redacted]'s treatment between January 2019 and May 2019

34. The week beginning 24 January 2019 there was still no firm plan in place, but, as the doctors knew that they would be doing some high dose chemo in the future, they wanted to harvest some of [redacted]'s stem cells so that they could give her some back after the high dose chemo. She had to have a light bit of chemo to make her body produce a lot of stem cells fast and then they harvested them. She had a week of chemo and then she had some blood drawn out through her Hickman line and then a machine sucks all the stem cells out and they are frozen. She was day patient for the chemo and then a week later she was in ward 2 for a couple of days as an inpatient for the stem cell harvest.

35. At this point the doctors decided to give [redacted] a round of another type of chemo, something called TVD chemo, until they had resolved the issue of the next stage of treatment. It was quite powerful and knocked her for six. We'd get to the point where she'd have the chemo in hospital and know she was going to spike a temperature three days later and be back in hospital. During her entire treatment plan, from October 2018 to August 2020, we weren't allowed to be more than an hour away from the hospital as if [redacted] spiked a temperature, the risk was that she had neutropenic sepsis. Because she had no immune system at all, she had to return to the hospital and to get antibiotics as fast as possible. Then the doctors would carry out some tests to see if she had an infection of any sort and we would know the results within 48 hours. In [redacted]'s case, I don't think she had any infections during the TVD period, I think she just had drops in her neutrophils because of the chemo and this caused her temperature to spike and make her really ill.

36. The purpose of this chemo was two-fold. Firstly, to stop things from growing while a treatment plan was discussed and; secondly, to try and shrink the tumours a bit further to allow [redacted] to get some surgery. The oncologist was really determined that she wanted to get surgery before we went to high dose chemo. Because the high dose chemo works on a surface area, the smaller the mass, the less it has to work on, and the more likely it is to be successful. So if they could get in with surgery and just remove some of the material, they had more chance of success. On the other hand, at this stage, the surgical team in Edinburgh thought they had to get a hundred per cent of the tumour out to be successful, but they were really worried about all the blood vessels. After each round of chemo, [redacted] would be scanned and the surgical team said they were not happy to operate. So [redacted] ended up having four rounds of TVD chemo, which was more than would usually be given. During the 4th round of TVD, [redacted]'s case was presented to the National Neuroblastoma Team, who discussed her, and said that they had recent evidence that suggested they didn't have to get a hundred per cent of the tumour. If they could just take as much as they could out, safely, that had a greater success rate than not at all. That was when [redacted]'s doctors returned

to the Edinburgh surgical team who said that they would be willing to operate.

[redacted]'s surgery: 3 June 2019

37. [redacted] underwent a major operation on 3 June 2019 to remove the mass in her abdomen. It was a seven-hour operation and the surgeons ended up removing one of her kidneys. It went well and the surgeons reckon they removed about 90 percent of the tumour in her abdomen.

38. Afterwards, [redacted] went to ICU for two nights. It was like an open ward so the medical staff could have clear line of sight on all patients. [redacted] had a dedicated nurse and she was very closely monitored. Once they were happy with her she was admitted to ward 3 again which we knew was going to be awful. This time we at least had a bed where I could sleep beside her. She had to go to ward 3 because they had the specialism to deal with surgical recovery, but we begged to go back to ward 2 which they let us do after a couple of days.

39. We were in ward 2 for some further monitoring just because the doctors didn't want to discharge [redacted] so soon after such a major operation. She recovered really well from it and she was also staring to recover from the chemo. She was discharged after 3 more days.

Preparation for High Dose Chemotherapy: June 2019

40. The next stage of [redacted]'s treatment was to undergo High Dose Chemotherapy. This was super strength chemo to try and take out the rest of the cancer left after the surgery. Normal chemo will knock you flat for a few days, and then you'll start to see your cell count rebounding. High dose chemo knocks your immune system out completely for up to four to six weeks at a time. Most of the management is about the side-effects that will happen as a result of that high dose chemo. It knocks out your immune system, but it also knocks out your digestive system. It has a high risk of damaging your lungs, so your

breathing is high risk. It is also high risk for your heart and your liver. Part of the preparation for this chemo was trying to get [redacted] in a good condition, and part of it was also understanding the current conditions of things like her heart and lungs. So the doctors did various tests at this stage to see what her lung function and heart function was so that they had a base level that they could monitor during the chemo.

41. The plan was that [redacted] 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 24-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.

42. When the doctors were deciding [redacted]'s treatment plan, they were having to factor in the move to the new hospital which was due to happen on 9 July 2019. As a result of this her treatment plan was affected. Once the treatment starts it can't stop so the doctors wanted to make sure that she was at a point in the treatment that they could manage her, and the effects of this chemo, the best they possibly could. They carry out the treatment about twice a year, so they had experience. The added wrinkle was that the new hospital was going to be opening during this treatment period. There was a lot of discussion between the team, as to whether [redacted] should stay in Edinburgh at all, or whether they should move [redacted] to Glasgow. Glasgow would have added complications for us as a family, but there was also concern at that stage about the infection risk in Glasgow. It wasn't said by the by medical staff, but us parents were very concerned about moving to Glasgow. We were aware of there being reports of infection control problems in Glasgow, in particular in the paediatric oncology department. There were other patients in Edinburgh that would normally be treated in

Glasgow but whose parents had requested treatment in Edinburgh because they had lost faith in the infection control in Glasgow. Parents talk.

43. And so there was that emotional element that they would have to try and manage. They also had to look at how many patients there were in Glasgow and whether they had the capacity to deal with [redacted]'s kind of treatment plan which is very resource intensive for staff. There was a discussion about the timing of [redacted]'s treatment if we were to stay in Edinburgh. They had to think about the best time to do it. I know there were significant discussions between some of the doctors about whether they should wait until after the move to start the treatment; whether it should start one week before the move; or whether it should start two weeks before the move. The risk of waiting is that there is something horrible growing inside [redacted]. There were so many different members of staff involved in these discussions. The oncologist, the anaesthetist, the HDU doctors, the ICU doctors, whoever might need to be drafted in needed to have a say about whether they would have the resources that would be able to respond to a child who's that sick.

44. The decision was made that [redacted] would stay in Edinburgh and the treatment would start one week before the hospital move, because that meant that her neutrophils wouldn't have dropped yet to their lowest point and it would be a safe stage in which to move her between two hospitals.

Information about the new RHCYP

45. At this point in time, all the nurses were going for tours at the new hospital, and had been for months before that. They would go off in groups on various days, and they would come back and wax lyrical about all the different resources, and what there was available. The cleaning staff would come back and rave about how clean they can make things and the auxiliary staff would come back and tell us about the parent kitchen, and the parent beds that were in the room, and the fact that there were toilets and showers in every room. We knew quite a lot about the new hospital at this stage, there

was an awful lot of talk about it. I can’t remember if we got a letter from the Health Board about the new hospital.

46. From what we had heard from the staff about the new hospital, we had huge expectations about it. We were really fixated on the Isolation room that [redacted] was going to be in after the move because we knew how risky the treatment was. We had been told that the isolation room was going to be off a separate entrance to the ward, so there wouldn’t be the normal footfall going past the room and the floor where you walked in would be clean. It also meant there was an extra set of doors between the ward and the isolation room, so again the infection risk would be reduced. Then the room itself was going to have positive pressure. That means air couldn’t come in from the outside, only air from the room could go outside. That would also lower the risk of infection as dirty air can’t be transferred into the room. It was going to be comfortable, it was going to be clean, it was going to be quiet. It was going to be somewhere that we could spend time together. The room itself was going to be ensuite and bigger than what we were used to. There was going to be room all around the bed and facilities for us staying overnight.

47. In terms of the ward itself, there would be a kitchen and somewhere for parents to sit. There was going to be a garden which was amazing as we could go outside with [redacted] in a wheelchair and experience some outside space. As I understand it, all the ward rooms would be single, ensuite rooms with a child bed and a parent bed and the day-care ward had beds that were in partially closed off rooms as well as a seating area where the kids could have chemo together. The only aspect we were not looking forward to was that we would have to pay for parking.

48. The other good thing that was going to happen was that the charity, CLIC Sargent, had previously had a house opposite the old Sick Kids Hospital. When the big move was originally announced, they'd sold that house in November 2018 and bought another one right next to the new hospital in Little France the same month. That provided lots of space, it provided

bedrooms for families who had come from far away, but it also provided care and emotional support for parents. They were going to be running support groups, and they had a masseuse that would come round, and they would have play specialists. There were going to be additional layers of support. We would be able to access that at the new hospital whereas we hadn't the whole time we'd been at the old hospital because it had been sold to coincide with the original opening date which had already been postponed.

High Dose Chemotherapy and Delay in move to the RHCYP: July 2019

49. [redacted]'s high dose chemo started on the 1 July 2019. She was initially on bed 8 in ward 2 which is was the worst bed. It's one of the beds in the corridor with a curtain round it. It was right next to the playroom and was very noisy. We were there for a week before being moved into isolation. At this stage [redacted] was allowed out of the hospital during the day and she was really well.

50. On 4 July 2019 my husband phoned me from the hospital to tell me that the hospital move had been cancelled. At that stage we had minimal information about what was happening. The charge nurse had told my husband that all she knew was that the hospital move had been cancelled and [redacted] would be remaining in the old hospital for this treatment period. I think the staff had been taken into the lecture theatre and told the move was not happening. The following day, my husband and I swapped, so he came home and I stayed in hospital. I was given the opportunity to speak to the Chief Executive of the hospital at that point, if I wanted to. One of the nurses came to me and told me that he was on the ward to speak with parents. I declined, because I didn't think I could manage my feelings at that stage. I didn't know who was at fault at this stage, I had no idea, and I didn't want to let loose at someone who might have had no control over the situation. I think, my husband and I swapped again, a day or so later, and then Jeane Freeman, the Health Minister, was on the ward talking to the doctors. I don't think that she was speaking to the parents, just the doctors, at that stage. My husband decided he didn't want to try and speak to her, because he was

too upset at what had happened. I can’t remember if we got a letter or anything in writing from the hospital explaining the delay.

51. 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, [redacted] 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. 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.

52. It seemed that the nurses on the ward had no information of what was really going on with the move. They were just as flummoxed as to what they could do. A lot of the trouble they had is that they'd already moved a certain amount of kit to the new hospital, and the staff told us that they weren’t allowed to get it back as the equipment was in clean rooms and it wasn’t clear how long the move would be delayed. They had to work out how to restock their cupboards. They had had things planned so that they would be finishing up with a certain amount of patients, they'd have a few days’

break to settle into the new hospital, and then get the new patients up and running. Now they were in a situation where they had to make sure they had drugs, kit and materials, for the new set of patients they had been expecting to see in the new hospital. They couldn't pause or cancel treatment, they had to keep going, and they knew they had to get things. There was a huge amount of logistical planning going on. On a personal level for some of the staff, some of them had moved house to cope with this new hospital move, some had changed their transport plans or their childcare plans all to fit around a new hospital, and were finding their lives were in flux as much as our lives were in flux.

53. Around this time the ward was generally in a guddle. Things were getting packed up and moved off and some of the nurses would be charged with packing up and moving things over to the new hospital whilst the other nurses are trying to continue with the normal day to day work. Their heads were in a different space, because they're trying to figure out, logistically, you know, how much of this kit do we need here, and how much kit do we need to have there, to make sure they could cope with this move. It didn't make any difference to the care [redacted] received. She still had a nurse dedicated to her for the day.

54. In terms of changes on the ward itself, once the move was cancelled, the playroom had gone. The toys and resources had either been packed up or given away or put in the skip because there were new toys and equipment at the new hospital. So following the cancelled move there was nothing for the children to play with until the staff got permission to buy new equipment or bring things back from the new hospital. In relation to the medical side of things there wasn't really an impact on that. The staff knew what they needed for the patients that they had in the hospital, and had planned to keep the kit that would support them. Much of the kit was nearing the end of its life and they had bought new equipment to replace it which was at the new hospital. The existing kit was still in place at the old hospital. They had planned it excellently, and thought of every consequence, and had it in place. They just didn't have any additional stuff, the "just in case" stuff, so

sometimes they might have to go to another ward to get something that would normally have been on ward 2. There was also a lot of kit that was reaching the end of its lifetime in ward 2 as there would be new kit installed in the new hospital. That meant the staff were working with older pumps, sats machines, obs machines, but they were still functioning, they just weren't the brand new "whizzy" stuff that was in the new hospital.

55. At this point in time, there was some chat from the nurses that the move might happen in autumn 2019, but really that was irrelevant to us as we were concerned about what was happening with [redacted] in the present. She was moved into Room 6 on ward 2. Although it was the best room facilities wise, Room 6 was where children go to die. We'd seen some children go in there and not come out so it was a highly emotional time for us, especially given how risky this treatment was going to be. The staff had discussed using Room 1, but it didn't have a toilet so we pushed back hard against that. [redacted] wouldn't have a toilet and as parents we would have to go backwards and forwards out of the room to use the toilet so it would increase the risk of bringing in infection. It was smaller and it was noisy as it was right next to the treatment room and nurses station. So despite the connotations of Room 6, it was the best room for [redacted]'s treatment to happen.

56. Although there had been an initial delay of a week in starting [redacted]'s treatment to compensate for the hospital move happening in the middle of the treatment, there was no delay to [redacted]'s treatment continuing once the move was cancelled. I think that we lost a day of chemo because one of the chemo fridges had been turned off in the run up to the move. Whether we can blame that on the hospital move or not I can't say for sure, but it feels like it happened in the guddle surrounding the move.

57. Once we knew that [redacted] was going into Room 6 she asked to go in early as a charity had bought toys and games for her to use during the isolation period and they were already stored in the isolation room. Although once we were in the room and the doors were shut and she realised she couldn't come out

again, she got very upset at that stage. It's a big thing for a little girl being told that she couldn't leave.

58. Once she was in the room we had to be very careful about infection control. We had to buy new stuff for her to have in the room that was still in its packaging and that could be opened in the room. We washed some of her teddies with antibacterial wash. Every other item that we took in there, we tried to wash at a high temperature. We wiped down toiletries, tablets, mobile phones before we took them into that room. If we were coming backwards and forwards from the room, because we wanted to use the toilet or go to the shop, we had a change of shoes at the doorway. I would leave my bag and coat hanging on a coat hook just outside the room. The staff would wash their hands before coming into the room, and they'd have to wear a pinny before coming in the room. If they had any form of cough or cold, they had to wear a mask. Only essential staff were allowed in, so student nurses were discouraged from coming in and a junior doctor would only be allowed in if there was a clear educational need. There was a real attempt to limit the number of people that were coming and going, and how they interacted with her.

59. Room 6 was one of the bigger rooms and there was a patient bed and then there was space to leave the parent bed out during the day, if we wanted to, as well as room for a chair and a table for [redacted] to sit at. The cleaner would come in every single morning and give the bedroom and bathroom a good clean.

60. Altogether, I think [redacted] was in isolation for four weeks. Towards the end of her admission, she was allowed out in the evenings to walk up the corridor when all the other patients were in bed. At the very end, I think she had a few days of being allowed out on the ward to mix with the other children, but was still an overnight patient. She was in hospital for the entire school summer holidays that year.

61. [redacted] became very ill whilst she was in the isolation room, although it was expected that this might happen. She started to be very sick, so much so that they had to switch off her food pump, and move her onto something called TPN, which means she was fed directly into the bloodstream, rather than into the stomach. She was put on a morphine drip because they were expecting her to get nerve pain. She started to get temperatures, but these were all expected. The doctors were telling us not to worry and they had it under control. Because she had a temperature spike, they had to treat her with antibiotics immediately, even if it wasn't actually an infection. A few days later they were worried about her saturation levels for her breathing and that was the first sign of a lung infection. She was put on oxygen, and the doctors were trying to work out what was causing her symptoms. They were not sure if she had a bacterial or viral infection and they started her on a broad spectrum of drugs. They were doing x-rays and ultrasounds to try and work out what was causing the infection. They wanted to do a CT scan, but they would have to anesthetise her to do this. That would run the risk of them having to ventilate her and would effectively mean putting her in a coma which they wanted to avoid if possible. Loads of senior doctors from different departments were in her room discussing what to do with her and eventually they decided to give her an endoscopy under light sedation. They had to take her out of Room 6 for this procedure to be done, which carried with it a risk of infection and I think the results were inconclusive. I think they eventually came to the conclusion that it was fungal, and with various different treatments, they managed to get her breathing under control. She was on oxygen for about two weeks in the end and she was nearly moved to the HDU, although the ultimate decision was that she could stay on the oncology ward.

62. In parallel to the lung issue, [redacted] also developed a liver condition, which is something that the doctors expected might happen. They were monitoring her weight and the diameter of her tummy daily and this is how they detected this issue. They then treated this with an infusion of drugs that she got every day for 28 days. This continued even after she was out of isolation.

63. In the end, because of these issues that had arisen, [redacted] was in isolation for a bit longer than she might otherwise have been, but the doctors told us it would probably be between four and six weeks for the total treatment plan, including 1 week before isolation, so she was out of isolation within that period and she was discharged on 12 August 2019. The whole period up to her discharge was about managing her to stop her getting sick. She was having blood transfusions, platelet transfusions etc. For the whole stay, she had one week of chemo, and then everything else was about trying to get her back to some form of stability.

[redacted]'s treatment between August 2019 and December 2019

64. Between August and October, [redacted] was still getting a lot of treatment as a day-care patient. She was getting an infusion every two days for her liver, she was still getting bloods and platelet transfusions regularly. But she was allowed to stay at home and she went back to school for a while. They then had to start preparing her for the next stage in her treatment which was the radiotherapy. She had to go in and get the mask made for radiotherapy. She needed this as they were going to be targeting areas around her neck so they needed to keep her very still. She would be bolted to the table with this mask with only little cut outs for her eyes and mouth and it can be very scary for children, so they started to do some kind of hypnotherapy to try to manage her emotions during the radiotherapy. The purpose of the radiotherapy was to zap whatever's left of the cancer. There was a lot of discussion and planning involved around what the treatment would involve and it took a few weeks to set it all up.

65. The radiotherapy took place at the Western General Hospital as that is where the radiotherapy takes place. It's in the adult cancer centre so not really child friendly, but they did their best. She had a specialist nurse as a buddy and they gave her a Lego kit of the radiation machine and painted her mask like a unicorn. She was there every weekday for three weeks and it was hard but she got through it. I don't think this has changed with the

new hospital opening, I think radiotherapy still takes place at the Western General.

Immunotherapy: December 2019- May 2020

66. The last part of [redacted]'s treatment was immunotherapy. [redacted] was due to get five rounds of this treatment as the doctors had identified early on that she was a slow responder so needed more treatment than was perhaps usually the case. This treatment is an attempt to create an immune response to neuroblastoma. There is a protein in neuroblastoma, and the treatment trains the body to identify that protein, and to kill that protein. It should suck up the last few cells of neuroblastoma in the body, but also in the future if anything was to grow back, it would ideally kill it before it gets a handle on the body.

67. To get this treatment, [redacted] was an inpatient and was attached to a syringe driver for ten days and the fluid was very slowly infused into her body. The first cycle can be a bit bumpy as your body reacts to the drugs. [redacted] was actually allergic to it so her first round was very bumpy and she was very sick and her digestive system gave up, which is what always happened when [redacted] got sick. She had to be fed intravenously again and they treated her with antihistamines. Her guts were inflamed and ulcerating and this caused her to develop C.difficile. This meant she had to be in isolation to stop her spreading the infection to others in the ward. She was in Room 1 for this stay and we were in for about 3 weeks due to the reaction that [redacted] had to the treatment.

68. The next round of treatment started again on 6 January 2020. It was planned for ten days, but [redacted] ended up being admitted for three weeks. She got c.diff again and was still reacting to the immunotherapy and this caused her to have a temperature and to feel quite unwell. This meant she had to go on antibiotics, which reacted with the c.diff, and it all just made her

incredibly unwell again. The same was then true with the third round. She got c.diff again, and that caused us a bit of a delay in getting home.

69. Her fourth round was in March 2020, and that's when the whole COVID situation was starting to come into play. She was put into Room 5 as she spiked a temperature and had a cough, but her COVID swab came back clear and we were shipped out of that room because someone had a cough and had to take the room from us. So we got moved to one of the ward beds in the corridor, that just had curtains, and we stayed there for the rest of the admission. Because of COVID, every time a room came free, another child with a temperature would show up, or a child with a cough would show up, and they'd have to get marshalled into one of those rooms and treated in isolation.

70. The fifth round of immunotherapy was in April 2020; COVID had kicked in and the whole ward was on lockdown. [redacted] had a room for this one, and once you were in, you had to have all your food and drink with you. We weren't even allowed exercise, I think, at that stage. It happened very suddenly, that the parents weren't allowed out. My husband phoned me to say he didn't have any food and had no way of getting any. A charity ended up delivering a whole pile of microwave meals to the parents. It was like this for the whole ten days, but [redacted] did really well during this round.

[redacted]'s ongoing care and experience in new RHCYP

71. After the immunotherapy finished, [redacted] had a series of scans and we got a call in May 2020 to say that she had gone into remission. She still has considerable follow up care. For the first year she saw the doctor face to face every month and then had a scan every two to three months. We have now moved to a slightly easier regime where we have a clinic every two months and scans every four months. In another year, it will move to clinics every two months and scans every six months and they do that for five years

and then [redacted] will be on the oncologist's books until she is 18. She will need follow up care because of some of the after effects of the chemo. We know that she will need hormone therapy replacement when she hits puberty and there might be other effects that we won't know about until she's older. She still gets dietitian support and we have access to a physio and support like that.

72. After [redacted] had gone into remission, we were still attending the old hospital as an outpatient. We no longer attended ward 2 and instead attended at the outpatient clinic. Oncology was the last department to move over to the new hospital so we were still attending the outpatient clinic and could see all the parts that had shut down. We then got an appointment letter which told us that the next appointment would be at the new hospital and it told us where to park and where to go.

73. We have only been at the new hospital (RHCYP) for outpatient clinic appointments, so we haven't been up to the new oncology ward that [redacted] should have been on back in July 2019. My husband went up to have a look, but I haven't seen it and although it would be nice to see what it is like, I don't want to have to go there. So I can't compare the ward experience in the new hospital to the old hospital, but from what I have seen of the new hospital it is impressive. It is clean, and a big, wide open space.

OBSERVATIONS ABOUT THE BUILDING

74. The old RHSC was not ideal as a hospital, although most of my attention was on the [redacted]'s care rather than the building. The building was irritating, and the toilet situation was horrible as she had to use the commodes and potties. I felt that was really degrading, but as a five-year-old child [redacted] just took it in her stride, it didn't bother her. The hospital was unpleasant for parents, but then it hadn't been designed to cope with parents; it had been designed for a time of life where you drop your child off at the door and pick them up in two weeks' time. Overall, I think we tended to find that the

building was letting the staff down. I think they were trying to do this tremendous job, and the building was limiting them sometimes. For example, they were trying to look after the infection control, but you'd see plaster coming off walls in places, and the maintenance guys would be around immediately that day, trying to patch things up. It was just a constant job of them trying to patch up things, to try and keep on top of the condition of the building, so that they could do the infection control. I mean, the cleaning staff were tremendous, but there's only so much you can do with the building as it was.

75. There were also the physical constraints of the hospital. There just wasn't enough room. For example, during the ward rounds the consultant comes in, then the registrar comes in, then maybe two junior doctors are trying to look over their shoulder and see what they're doing. A pump then alarms because they need a new change of IV bag and everyone has to shuffle around so that things can be done. Those rooms are only designed for the child, the parent, and one doctor. Another example was if an ultrasound was required and the child was too ill to be moved, a portable ultrasound machine would be brought in and it is huge. To get it into the bedroom, almost all the furniture needed to be removed from the room. If the child is upset and scared, they want mum to hold their hand, but there's no room for mum. On some occasions, I had sit on the windowsill to try and hold [redacted]'s hand whilst the doctors/nurses were dealing with her. Those are the kind of things that let the staff down, I felt.

76. Most days there'd be something, either just off the ward, or in the ward, that needed a bit of fixing, and fiddling. Sometimes they'd be fixed immediately, sometimes they might be out of bounds for a little bit, until they managed to fix it.

77. At one point, one of the taps in the treatment room had bacteria, it was the same one that was going on in Glasgow at the time. The water was tested every day and this tap was condemned. We were told about this by the nurses on the ward and we also had a letter delivered to us telling us what

had happened, what they were doing to address it and pretty much telling us not to worry. I got this letter from the Ward Nurse but no longer have it. Some of the parents on the ward were going back and forth to Glasgow and were fully aware of what was going on there. Then there was the period where the Glasgow ward was shut, so a lot of the nurses were deployed into our ward. I can't recall specifically when this was. Our nurses were telling us some of their observations about these Glasgow nurses, and how they didn't want to wash their hands in the taps, they didn't want to use the running water and would use bottles of distilled water. One nurse said to me, that it was like they've got PTSD, and it was as if it was scary for them to be around running water.

78. It was only this one tap that wasn't to be used. We were allowed to use the taps in the bathrooms and in the sinks in each of the cubicles. We never used the water for drinking, it was purely for hand-washing, teeth-brushing, that kind of thing. Generally, the children couldn't reach them because they were beyond the hospital bed, and they were attached to a drip-stand, so they couldn't get them. So, it was the parents and staff who would use the taps and there were sinks dotted all around the ward. Hand-washing was a continuous thing in this place. Something everyone is now used to, with COVID times, but we were already very used to washing our hands regularly. As soon as you came into the ward, you had to wash your hands, you would not have been allowed in by the nurses otherwise. Every time you touched a syringe, every time you touched a pump, every time you've touched various surfaces you would have to wash your hands again. Parents and staff worked hand in hand in relation to infection control, because infection risk is so critical for these children, who had no immune system, and so a normal cough or a cold could be utterly awful to them. If the doctors had a cold, they would come in wearing a mask that day, and they might be wearing a pinny, depending on the infection risk of the child. They would wash their hands before they touched the child, they'd wash their hands as soon as they'd touched the child as well. It was stringent infection control. Every morning the cleaners were going around all the surfaces with disinfectant, and the floors. Beds were changed every single

day, wiped down, cleaned down. When a child left the hospital, the entire contents of the room they had been in were taken out and deep-cleaned, and put back before the next child could come in.

COMMUNICATION ABOUT THE DELAY IN MOVING TO THE NEW RHCYP

79. As parents, we did not have any formal communication from the hospital or the Health Board about why the move to the new hospital had been delayed in July 2019. I only heard about the reasons for the delay from what I read in the press. It was to do with the air exchange in the isolation room, which was one of the critical flaws in the new hospital, and that was the reason why they had to stop the move. It was because the air exchange had been inappropriately put in, and it wasn't going to be sufficient for the needs of that room. I think there were also some comments and jokes from the staff on the ward about the builders in the new hospital being crap. The staff in the hospital were very open and frank with us and told us what they knew, which was not a lot. There was one point that there was some discussion that the hospital would move in autumn 2019, but our oncologist thought it was highly unlikely to happen, and sure enough, it didn't. By that point the staff didn't believe any date that they were told and were just carrying on with their jobs in the old hospital as best they could.

80. There was never any communication from the Chief Executive of the hospital, or anyone in management to us acknowledging the delay or the effects it had on the patients and families. Yes, the Chief Executive had been on the ward at the time of the delay but we were focussed on [redacted]'s treatment and too upset to speak with the Chief Exec at that point. It was a similar situation when the Health Secretary visited the ward. I was maybe given a post-it note of someone I could contact in senior management if I wanted to contact them. This was at the time of the delay, but as far as I am aware, we weren't given any other opportunity to speak with anyone from senior management after that. All I was aware of was things that were in the press. I saw the Health Secretary talking in Parliament and I saw quotes

in the press. There was mud-slinging going on, between the politicians, and they were very much talking about the hospital building, but they weren't talking about the patients, and the children, and the effect on those people. I found it incredibly upsetting that they weren't talking about this.

81. I don't think the way that the Hospital/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 taken for a good reason. The staff were communicated with, but the parents were not communicated with. We got the trickledown 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 is almost as if management think that because the patients in a 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, but they don't communicate with terribly well.

82. Since this all happened in July 2019 I don't think we have had any communication from the Health Board in relation to the delay in the opening of the new hospital. In fact, the only thing we have had is a letter from them recently suggesting that we get in touch with the Public Inquiry. I no longer have this letter.

COMPLAINTS

83. I didn't make any formal complaint in relation to the delay, the lack of information surrounding the delay, or the failure to acknowledge the impact on the patients. I did vent my frustrations to the staff on the ward and all the nurses agreed with me. For them, children are the entire reason that they are at work each day. I also spoke to the press at that point, because I was so cross. I wanted them to centre their articles around the children as I felt that element was missing quite badly. It was really frustrating to hear the

politicians and the press banging on about the physical structure of the hospital, and not about who goes in that building, and why this building was important to them. I didn't put a formal complaint into the hospital, because I didn't know whose fault it was at that stage. We were also dealing with an incredibly sick child at that stage, and no complaint I could make would change things. It was not for me, at that stage, to make a complaint, I didn't see the value in it. I hadn't thought about making a complaint later on and, to be honest, seeing the advert for the Public Inquiry was the first time I had felt able to deal with the issue.

EMOTIONAL IMPACT OF THE DELAY

Impact on [redacted].

84. From [redacted]'s perspective, she had had a shiny new toy waved in front of her, and then whipped away. She was unhappy that she never got to experience all these things that she was told she would experience in the new hospital. Oncology kids have really low expectations in life when they are undergoing treatment as all their opportunities have been whipped away from them, so little things matter. We had been told that a lovely chap had bought a little mini McLaren electric car for the new hospital that children were going to be allowed to drive themselves to surgery in. We'd been allowed one shot on it in the old hospital, and then it got put back in a cupboard because it wasn't appropriate for that space. [redacted] had been promised a "blue light" in the ambulance when she was being moved to the new hospital and that she was going to be a special VIP patient. She also thought she was going to get a bead for her treatment bracelet to say that she had been in an ambulance. So we had to then manage [redacted]'s emotions as a little girl who had been promised things that didn't transpire. She was very upset when none of those things happened and would often ask when she was going to get to go to the new hospital. When it transpired that she wouldn't get to go at all, that also upset her.

Impact on witness

85. Initially when the move did not happen we were very, very upset. At the time, we were very scared that not moving to the new hospital would mean an increase in risk for [redacted] who was at a very risky part of her treatment. We had been told by the medical staff that they thought that they would be better able to manage the infection risks in the new hospital, so when that option was removed from us, it was a blow. Then it almost became a bit of a running joke of, "*all the things we could have had*". We used to joke that we weren't worthy of this new hospital.

86. As it transpired, one of the major problems about the new hospital was going to be the room [redacted] was moving to, from what the press was reporting. That being the case, ultimately, we actually felt relief that the move had been cancelled as that might have actually been a bigger risk for [redacted]. It was a situation where we didn't know where the greater risk was; the old hospital or the new hospital.

87. It was also very upsetting for us that there was no acknowledgment of the impact that the delay in the move had had on the patients, particularly the children.

CONCLUDING COMMENTS

88. It's still incredibly tragic that the hospital move didn't happen properly the first time, because I think it is probable that, if it had, some children might have been saved, or at least they would have been saved a huge amount of discomfort and pain by having the facilities in the new hospital, but that's not for me to say.

89. By not having a hospital move, it caused a lot of emotional upheaval, and concern for patients and their families that was unnecessary. It had already been a very long build as it was. There had already been a previous delay from when it had originally meant to open, and then the move was cancelled

at the last minute. Surely the number of checks that had been done to that point meant they should have been able to catch any issues, and reduce the impact that we were all dealing with later.

90. If the Health board have contracted to 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's seems to be a classic case of public sector organisations trying to project manage something they don't have much experience in. There must be lessons to be learned.

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