Scottish Hospitals Inquiry

Witness Statement of

Abhishek Behl

WITNESS DETAILS

1. My name is Abhishek Behl. I was born on [redacted]. I am [redacted] years old. I am [redacted] .

2. I am the father of [redacted]. [redacted]'s date of birth is [redacted] . She is four years of age.

3. I live with my wife, [redacted], and [redacted] at our home in [redacted].

OVERVIEW

4. My daughter is [redacted]. At just 6 months old, following a number of seizures and other episodes, [redacted] was diagnosed with a one in a million neurological condition – Alternating Hemiplegia of Childhood (AHC). Only 2 children in Scotland and 55 in the UK have the condition. It involves many neurological symptoms, including paralysis, dystonia, seizures, ataxia, global development delay, epilepsy, and life threatening apnoea (breathing difficulties) requiring intubation and ventilation in Intensive Care.

5. Since being only 5 days old, [redacted] has been a regular attender at the Royal Hospital for Sick Children (RHSC) in Edinburgh, both as an in-patient and as an out-patient. During her many in-patient stays, [redacted] has most regularly been in ward 7 of the hospital, which is the Neurological ward, though she has been in several other wards.

6. I can speak to the impact on [redacted]'s treatment as a result of the delay in opening the new Royal Hospital for Children and Young People (RHCYP). I am also a member of the Family Council at the hospital and, in this capacity, I was able to

have a familiarisation visit with the Council to the new hospital and see the improved facilities that it would provide.

FAMILY BACKGROUND

7. [redacted] lives at home with me and my wife [redacted]. She is our only child. [redacted] is a hospital doctor, but she is in geriatrics and internal general medicine, which is totally different from paediatrics. [redacted] is currently doing research work, studying for her PhD in dementia and Alzheimer's disease.

8. Despite all her challenges, [redacted] is a really happy child. She is bubbly and a people's person, always chatty and she loves interaction with people. She's strong and full of life and laughter. It can be really difficult for her when her condition causes paralysis or dystonia, but she is remarkably robust and has a high pain threshold, meaning that we need to take extra care if she has any bumps or accidents, because she doesn't always cry or indicate if she has done herself any damage.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT THE OLD SICK KIDS HOSPITAL

9. Our experience with the Sick Kids hospital began on 4 August 2017 when

   [redacted] was only 5 days old. She went to A&E with twitching in her legs, known as fasciculations, and jaundice. In the first year of her life, she would go on to have about 40-50 blue light ambulance trips to A&E at the hospital, as we had to call 999 when [redacted] experienced severe neurological episodes/seizures.

10. On that first trip to A&E, it was one of the medical staff from neurology, the registrar ST5 or ST6 grades I think, who dealt with [redacted]. We had actually taken a video of the fasciculation as sometimes the symptoms last only for a certain period so don't show by the time we're at the hospital. From [redacted] being very young, we have made loads of videos of the episodes, because we learned early

on that [redacted] would often be fine by the time we reached the hospital, so it was better that we would have the video to show what had been happening. If an episode is not controlled within a certain time, it can end up as a seizure.

11. There was no treatment needed for her neurological symptoms during that initial visit, as the episode had stopped, but the video, and future videos of different symptoms, that we had taken gave the consultant the first indication that [redacted]'s condition might be related to a channelopathy, a neurological condition. This, and her seizures not responding to anti-seizure medication, are what led to getting genetics testing.

12. My wife explains a channelopathy as where, in the cell membrane, you have various channels of different kind of pumps that move the ions, like potassium, magnesium and calcium, in and out of the cell. Because of that movement, they might set off a chain of reactions where you suddenly then start contracting a muscle, or you start sending a nerve signal. If there is a problem in those channels, in the pumps that pump things in and out of the cell, then that's what they call channelopathy. It's a massive term covering different conditions, but ultimately they all have a problem with the channel and the ions going in and out of the cells, or the direction of movement, so you might not get the right signal for a nerve conduction to trigger the right movement, or it might trigger seizures.

13. I can't recall the balance between [redacted]'s in-patient stays and the outpatient visits but she was often an in-patient, for the likes of 5 or 10 days at a time. The treatment often involved prolonged electroencephalograms (EEGs), which monitored brain activity. It was [redacted] who would stay over with [redacted] because she was breastfeeding at the time.

14. With the frequency of visits, [redacted] now has an anticipatory care plan. This means that the Ambulance Service knows her situation when we call them from her phone, which is in her red bag. This red bag is her emergency bag, which basically has all her medications, her epileptic drugs, oxygen, her SATs monitor, her suction and basically everything she needs. And when we give a call 999 from this phone and it goes to the emergency services, they ask us the normal first few questions and then they have an anticipatory care plan that pops up for

them as well, about [redacted]'s condition. So we as parents don't have to explain each and every detail of what the condition is all about, each time. It's a great platform.

15. [redacted] is on a large amount of medications, maybe more than 25 medications a day. This takes a lot of planning and stocktaking, because the meds have short life spans and we need to ensure that they are used in the right order. We have two cupboards dedicated just to [redacted]'s meds and we have a book that we have maintained since she was just two years old, where we keep a careful record of everything that she is given.

16. [redacted]'s first severe seizure was in October 2017, when she was around 10 weeks old. She stayed in ward 7 of the hospital for a few days while they did EEGs on her but the doctors couldn't find anything at that point.

17. [redacted] had further episodes in the weeks that followed. She had several hospital admissions, roughly every four days, into November 2017, including when she was an in-patient to allow the hospital to do a prolonged EEG in order to capture imagery for her seizures. Despite what were becoming continuous episodes and seizures, and an MRI scan which is quite rare for such a young child, they were still unable to diagnose the cause.

18. The pattern of further admissions, sometimes for several days at a time, continued over the next couple of months, as [redacted] continued to have episodes and seizures and the consultant continued to do tests. Eventually, in February 2018, when [redacted] was 6 months old, the diagnosis of Alternating Hemiplegia of Childhood (AHC) was made.

19. After the diagnosis, [redacted] continued to have episodes each week. An episode would often involve her arm going straight, her eyes deviating and going to the left, like nystagmus. Episodes could develop into seizures, which could be severe, especially when they resulted in apnoea and [redacted] would become dystonic and her chest wall would tighten.

20. The seizures can also involve respiratory arrests, when [redacted] requires intubation and ventilation in Intensive Care. This has happened six times and it is really distressing for us as well as [redacted]. My own view is that there should be more

support for parents in this situation, counselling perhaps, because there's nothing to prepare you for what this condition brings to your life and that of your child. It's important that we remain calm around [redacted] and this can be really difficult when witnessing her seizures.

21. In May 2018, there were only one or two admissions that I can recall, although there were more outpatient appointments. There was also a 5 day ambulatory EEG at home, which was to avoid a further lengthy hospital stay.

22. There were fewer admissions over the following year or so, though there was a brief admission to the Cardiology ward of the Sick Kids hospital in Glasgow in May 2019. Cardiology is shared between the Glasgow and Edinburgh hospitals and this was for [redacted] to have a cardiac monitor implanted, between her stomach and chest (under her chest wall), meaning that the symptoms during an episode or seizure could be relayed directly to Glasgow and recorded. It's a very impressive system.

23. During this admission, which was for two or three nights, [redacted] was woken very quickly from the general anaesthetic, which is not good because sleep is such an important factor with her condition. She began to deteriorate and ended up in Paediatric Intensive Care Unit (PICU) after going into respiratory arrest. We had a very bad experience with [redacted]'s treatment at the Glasgow hospital, including when she was left for about 40 minutes in PICU while the nurses were chatting with each other about what to do and my wife [redacted] had to intervene to say that they needed to put suction in her mouth before she choked with the frothing that we could see. She also had a seizure for almost an hour and there was a delay in administering medications to get her out of it. In PICU, no one came from Neurology to see [redacted]. Eventually the Neurology consultant came the next day, but said to us that we should give notice when [redacted] was coming in, as if we could predict these kind of emergency things. The facilities in the Glasgow hospital during our stay were great, like a 5 star hotel, especially compared to what we were used to in the Edinburgh Sick Kids, but our experience of [redacted]'s treatments was horrible. We did consider making a formal complaint but we didn't have time to do that.

24. I guess that a positive from our brief Glasgow experience was that it highlighted even more how great the medical treatment was that [redacted] was getting in the Edinburgh hospital. Maybe if we had a longer time in the Glasgow hospital we'd have seen problems with the building, but we stayed in the Ronald McDonald facility, which was great and the staff were really helpful, so our issues with the Glasgow hospital were only about [redacted]'s treatment.

25. The pattern of [redacted]'s attendance in Edinburgh Sick Kids continued and in June and then July 2019, she was taken to A&E and then PICU as she was not breathing. This happened regularly and she was treated. We were told to pay careful attention to [redacted]'s condition after she was discharged home from PICU, as the following 24 hours were always critical. But they said that if anything happened, we should not return to that hospital and the new one would be open the following day and we must take her to the new accident and emergency as the old one would be closed. Everyone knew that the move of the hospital was due to take place at some point in the next 24-48 hours, though not when, but we could see that staff were literally packing up lots of kit, equipment and toys and things, and the staff themselves seemed excited that move was actually happening. The news was very sudden after so many prior delays.

26. Later that day, or possibly early the following day, we were astonished to read a friend's post on social media, I think it was Facebook, highlighting the news that the move wasn't actually happening after all. I don't recall the details, only that the move was delayed, and I don't think it gave timescales. We found this difficult to believe as it was a matter of hours, and certainly less than a day, since the nursing and medical staff had been saying that the move was going ahead the next day.

27. [redacted]'s next attendance was in August 2019, because she was struggling to swallow. Her tongue would sometimes become dystonic, so a kind of contraction, needing hospital treatment for fluids as she couldn't swallow and she was admitted for several days on this occasion. By this time, it was noticeable that the wards had virtually no toys to keep kids occupied as they had been disposed of in preparation for the move that didn't happen. Keeping a child occupied when there are no toys or anything to distract her attention just added to the challenges.

Also, the WRVS coffee shop had shut down in preparation for the move and so there was limited options for parents in hospital with their child to get refreshments.

28. Regular visits for various treatments continued to the old hospital until February 2020, including surgery in January 2020 for placement of a gastrostomy feeding tube in her stomach, but were minimised from March to June 2020 because of the Covid pandemic. In August 2020, there was a further admission to A&E when

   [redacted] had stopped breathing and required ventilation. There followed mainly out-patient appointments for the remainder of 2020 and there was a period going into 2021, when some out-patient appointments were at the new hospital and some at the old hospital, depending on what was being treated.

29. It was in March 2021, more than 18 months after the move was supposed to have happened, when [redacted] was actually admitted to the new hospital for the first time. We were actually the first people in the EEG (neuro-physiology) department at the Neuro ward and [redacted] was actually given a certificate for being the first patient they ever had at the new place. She had several days stay as an in-patient, including for EEG monitoring, and then later had another stay (10 day stay) at the end of March/start of April. She has had further out-patient appointments since then.

Facilities at the old hospital

30. [redacted] was most often admitted to ward 7, the Neuro ward. It had 12 beds, with six, four and two across three cubicles, one of which was for EEG monitoring. It was important for the nurses to be able to see [redacted] so she was generally in the bay with six beds, as this was nearest the nurses' desk.

31. When [redacted] was staying over at the hospital with [redacted], most of the time she slept beside [redacted] in [redacted]'s bed. [redacted] was offered PJ's Loft to stay in, but it was quite a distance away and [redacted] was breast feeding so didn't want to be away from [redacted]. I think [redacted] did use PJ's loft once just to get some rest

but most times she was given a room sharing with someone else. It was a room with two beds, and you'd basically have someone sleeping in the next bed. They wouldn't mix sexes but I thought that was terrible as parents couldn't always be together if no space.

32. [redacted] was often in different wards at the hospital. She's been in wards 4, 5 and 6 at various times. This was generally if she had been admitted with a bug or infection, and needed to be in a single cubicle. There was only one such cubicle in ward 7 so it wasn't always available. When she wasn't in the Neuro ward, it was never a good experience. There would be lights on at nights, flashing lights from SATs monitors and other equipment and lots of things we didn't have to contend with in the Neuro ward, as they understood her condition. Flashing lights were a trigger for some of [redacted]'s episodes but staff in the other wards wouldn't always understand this and, if we asked them to switch some of the lights off, they'd say that they needed to keep them on. As [redacted] needed a cubicle for limiting triggers and wakening from sleep which is dangerous, we would often be put on another ward that had a cubicle and be a 'boarder.' It was not a good experience being a boarder. If we buzzed for advice or reviews, they would often not send the ward staff in and instead call neurology who might not be able to come to the ward for some time. Some nurses were excellent, but some made you aware that you weren't on the parent specialty ward and were a 'boarder' so they didn't learn about [redacted]'s condition.

33. The WRVS canteen was fine to a point, before it closed. There was a kitchen facility in PJ's Loft, but it was difficult for [redacted] to get there when she had to be with [redacted]. Quite often, I'd get [redacted] a takeaway, maybe a pizza or Chinese or something like that, to keep her going, however no hot food was allowed on the ward so we struggled to find a space to eat. Food was a real issue for [redacted] when she stayed at the hospital. She would be given breakfast, which was basically cereal, but left to her own devices for the rest of the day, despite the fact that she was breastfeeding [redacted]. The canteen closes early most daysy, around 5pm, and at the weekend was often only open for a half day. There was a microwave, but it was supposed to be for patients only, so we didn't want to get staff into trouble by asking them to heat anything for [redacted],

taking them away from their duties. As it wasn't easy for [redacted] to leave [redacted], often she just had to wait for me to come in with food and she hadn't eaten anything except her cereal in the morning. It wasn't a good situation. A baby needs breastmilk at that young age and the mum needs foods and fluids to be able to give the baby nutrition. Sometimes there was left over food on the trolley that was going back to the canteen to be binned, and once or twice the nurse gave [redacted] some of the leftovers as she could see she hadn't eaten and was breastfeeding [redacted]. Sadly, those nurses then got into trouble for doing that.

34. Even getting drinking water for [redacted] was a challenge when we were there as there were no kitchen facilities for parents on the wards and the tap water in the toilets was only for washing and not for drinking. [redacted] had to ask staff to fill her water bottle for her, which again wasn't ideal when the staff were busy. When breastfeeding it is vital that the mum drinks lots of water otherwise there can be difficulties in maintaining breastmilk supply.

35. Before the planned move, facilities for the kids were actually pretty good on ward 7. There was the play room and play staff and there was stuff that catered for all ages, from babies and toddlers to young adults. There was a PlayStation, DVDs, all that kind of thing, so plenty to keep the kids occupied.

36. The lift in the building was poor. Often it wasn't working and, even when it was, it was the slowest lift you could imagine, to the extent that a lot of people just didn't use it.

37. Other facilities that you take for granted these days, like facilities for breastfeeding mums, just didn't exist. Most mums want privacy for that kind of thing, but their options were limited.

38. Overall, I think that the old hospital just felt like a makeshift place, where they knew for years that a new hospital was being built and they just basically made do with what was in the old place for as long as was necessary. From a non-medical point of view, I think it was very poor and the nursing staff did well just to keep it functioning.

Deterioration of facilities at old hospital

39. I mentioned that the toys had been removed in July 2019, in preparation for the move. I think it was for health and safety reasons that they couldn't be taken to the new hospital. The nurses actually gave [redacted] a bouncing ball she sat on that she really liked and we were able to take it home or it would otherwise have been disposed of. This was good but it became really difficult to keep [redacted] amused over the long period that we had to go back to the old place.

40. Thankfully the play staff were still there. In Neuro, we had Audrey. She is brilliant and she has known [redacted] since [redacted] was only days old, so Audrey can work around the lack of toys and keep her entertained. But there were other kids in there and, without toys and without books, it must just have been really difficult for them.

41. Another big loss was the WRVS cafeteria. It had actually closed before the planned move, I can't recall precisely when, but it just removed another option, especially for [redacted] when she was staying in the hospital. So we had to go out to the shops and fortunately there was a Victor Hugo café out at the Meadows so at least there was somewhere we could get food.

42. The main cafeteria was impossible for someone in a wheelchair to get to, stuck upstairs at the back of the building. It was crazy that it was put there in the first place.

43. We were lucky to have the Sick Kids Charity shop, but they only had a limited range of sandwiches and if you were a bit late, then everything was gone. The option then was to go outside but that meant leaving your child and if you were there on your own, this was difficult and you had to ask a nurse to watch your child when you were away. With [redacted]'s condition, many of the nurses were unfamiliar with it or what to look for in her symptoms so it was not easy to leave her. They were also often very busy covering the ward and didn't have free staff.

44. There was an impact on the medical equipment too. [redacted] had an MRI scan in July 2019 while being intubated in PICU. The staff had told us that the MRI equipment was newer and much more sophisticated at the new hospital and they said they would have preferred doing [redacted]'s scan at the new place, because it would

provide better imagery. [redacted]'s hasn't actually had an MRI at the new hospital but I think that is because her needs have changed and she has a different consultant. But when she got the MRI that was needed in July 2019, this was done on the old MRI machine because we were still in the old hospital.

45. I likened the situation to the hospital having limped along with one leg as it prepared for the big move to the shiny new facilities but that leg was effectively chopped off too at the point that the move was postponed, because we were just expected to make do with what was left until the move eventually happened. It was already a makeshift hospital that had seen better days, which was why the new hospital was needed in the first place, but people were expected to keep it going until the new place was available.

46. I have to take my hat off to the staff who kept the place running. They were affected by the delay as well as the patients and families and they had to keep things running, making sure that patients were looked after despite the challenges of the environment.

47. The internet rarely worked and there were kids who virtually lived in the hospital who struggled to do their school coursework because they struggled to get on their websites. That had been an issue for a long time at the hospital and people were looking forward to finally leaving that problem behind them at the old place.

Experience at the new hospital

48. We have now had quite a bit of experience at the new hospital. It has more cubicles, so we're not relying only on the one EEG cubicle on the neurology ward, which at the old hospital meant us sharing with someone else when

[redacted] was being treated. This makes things better for us and [redacted]. And inside the glass of the doors, there are shutter-type blinds, meaning that the light outside the cubicle can be blocked out and we can darken the room when that is required. However, the light is only partly shut out so at night the light from the door can be a lot and we had to cover with additional paper to reduce the light exposure to [redacted] which can be dangerous during sleeping times.

49. The new place also has an adjoining bed for when a parent is staying over, and a toilet adjoining the cubicle, which is such an improvement on what [redacted] has had to experience at the old Sick Kids.

50. While it is a huge improvement on the old hospital, there are still lots of things that I don’t think are right at the new place. A lot of that is on the administration side. Things like fridges, where they seem to be owned by the catering department and nurses have no control over what food is kept or removed, are actually worse than they were before. For example if [redacted] has ketogenic food, which goes in her gastrostomy, her tummy button, we make it and she takes a little bit of it and we have to put the rest of it back in the fridge. The catering staff will sometimes remove and bin it, something we didn’t have to worry about at the old hospital. Even the consultant wasn’t happy about this and suggested I raised the issue through the Family Council.

51. There are other things about the new hospital, nitty gritty things like the temperature and the lighting that could be better, but I guess it’s a new place for the people there as well.

52. I think the space could have been used better. There’s loads of space yet the cafeteria on the ground floor seems so small. The staff and the customer service in that new cafeteria are just amazing, but I can’t understand why it hasn’t been given more space.

53. One of the things I think that they got wrong at the new Sick Kids hospital was the naming of the wards. They went for Scottish castle names, like Borthwick, Tantallon and Castle Mey. My daughter will struggle to pronounce the names of wards she’ll be in and I really don’t know why they didn’t go for simpler, child-friendly names. They could have kept the Scottish theme but used something like animals or birds, so the Red Deer or the Gannet or Osprey ward. They could even have had a Unicorn ward and at least younger kids could have related to it. I don’t know what consultation they did about the names, if any. The names

aren't inclusive for parents or children unable to pronounce them. They also can't differentiate them for instance the picture to describe all the wards is a castle whereas most children's hospitals use names that have multi-sensory impact so those children that can't read or speak can recognise a different picture of a different animal for instance. It must be frightening for children unable to pronounce or understand these complicated names when being orientated back to their ward after surgery or procedures. I understand that nurses may have been given a say in the names, but they had a very limited menu of options to choose from.

54. And the new wards seem to be the same colour, beige or brown. Again, they could have made them more colourful and attractive for kids and helped differentiate the wards for children of all ages, as well as those with learning disabilities, to help orientate the children to their ward.

55. One of the things that is being discussed by Family Council is the need for a six months or one year review of the new place, what's working well, what isn't and what action is needed to make things better.

COMMUNICATION

56. Communication about the delayed move was virtually non-existent. After we heard from friends on the day the move was supposed to take place in July 2019 that it wasn't happening, we got a letter, maybe 3 weeks later. It basically said that any appointments planned at the new hospital should continue at the old one. There was no information about the cause of the delay or how long it would be for, nothing really. I can't recall who sent the letter and I haven't kept a copy.

57. What was really poor was that even as a member of the Family Council, whose role is to represent the patients and families and engage with those running the hospital, I knew nothing about the delay. As a parent, I can just about accept that there was a communication failure but what is the point of the Family Council if even it didn't receive any information about the delay to the move. We knew nothing more than what we were reading in the newspapers. Fiona Mitchell was

the Director – I think of Women and Children Services - and she worked really hard with the Family Council. I think she could have told us but maybe even she didn't know what was happening.

58. We did try asking some of the nurses for an indication of how long the delay would be but they seemed to be as much in the dark as we were. They said that, like us, they still thought right up to the day of the planned move, or maybe the day before, that it was going ahead. I know that they were surprised and disappointed at the delays and I'm pretty sure that they would be happy to tell you that themselves.

59. I do actually wonder if even the managers knew what was happening. Clearly, the decisions had been taken above Fiona Mitchell's level but there was a serious failure of communication in letting those who would be most affected – the patients, families and staff – know what was going on. Though the new hospital is now up and running, I still don't think it has been communicated why there was such a delay. I can only guess it was a safety thing. There may have been good reasons and people might have actually understood and agreed with the reasons, but I can only stress again that there was no communication, either with parents directly or with the Family Council, so people were just left to get on with it and deal with the uncertainty.

60. Even when the hospital did eventually move, I don't recall any communication with me as a parent. I think I became aware through the Family Council and from the media, but I don't recall any direct engagement with parents or families.

61. As a family, we have been quite lucky because we have such regular and close contact with the nursing teams and we just need to send them a message or text them and they will give us a call straight away. Other families don't have that kind of structure in place, so the communication could be very difficult for them.

62. I think management at the Health Board need to understand that some families have kids who spend literally 100-150 days per year in the Sick Kids hospital. For these families, it's not enough to just tell them what's happening, although any communication at all would be better than what we have been used to. But they

should engage with these parents and ask them what they think about plans before making definite decisions about things. Who is better placed to comment on the proposals than families who spend such a large part of their lives at the hospitals?

IMPACT ON FAMILY

63. It’s really hard to assess the impact on [redacted]. She is too young to understand what’s happening and for us as parents, it’s our job to shelter her from the negative things about the hospital and all the uncertainty about the move. And it’s not just her age but her medical condition that would make it difficult for [redacted] to understand everything that has been going on around her.

64. From a medical point of view, one big thing that [redacted] missed out was not being admitted more often. By that I mean that we tried to keep her away from the old hospital as much as possible. We knew that in the new place, we would be able to get a cubicle, like the single rooms I’d seen as part of the Family Council visit to the new hospital, and we would be able to make it dark and quiet, so we would have an environment where [redacted] would be safe and her condition would be properly catered for. We could never be certain of getting that kind of thing in the old place, so we avoided going there as much as we could.

65. We would sometimes call the old hospital the Christmas tree, because there are lots of triggers for my daughter’s condition and light is a big factor that can cause her to get an episode. Bright lights trigger episodes, and noise can too, so I called it the Christmas tree because, to me, it suggests enjoyment, it's about happiness, it's about excitement, it's about festival, rather than the calm that [redacted] needs. And sometimes the hospital, pre-COVID, used to be have parties happening, with siblings and families coming in, understandably wanting to make the patient happy. But that meant it could be pretty noisy and that wasn’t good for [redacted], so there were times we chose not to take her in, because we thought it might make her situation worse. At least at home we could control the environment and we

could rely on the ambulance service and the paramedics, who were always amazing.

66. As I have said, examples such as [redacted]'s MRI scan being done on the old equipment, when the staff had told us about the more advanced scanner that would be available at the new hospital, showed us that [redacted]'s medical treatment was being affected by the delayed move too.

67. From the perspective of [redacted] and I, as [redacted]'s mum and dad, the main impact on us was because of the uncertainty and the sense that we were missing out on a much better hospital experience for [redacted]. I have talked about just how frequently she needs to attend, and having to keep going back to that old outdated hospital, when we had been expecting the hugely improved facilities at the new place, made us really frustrated. The first admission when [redacted] was 5 days old was difficult for [redacted] who was post-natal with wounds that needed midwives as well as staff used to caring for a new mum and child together. Often in this post-natal period both mother and baby would get admitted to the post-natal ward at Simpsons at the Royal Infirmary. As [redacted] also had neurological symptoms as well as jaundice, she had to be admitted to the old Sick Kids hospital. This was not designed for newly post-natal mums and [redacted] was unable to be seen by a midwife and unable to have access to a shower easily. Had the new hospital been opened at that point, it would have been in close proximity to the maternity and post-natal wards of Royal Infirmary and she could have received the appropriate post-natal care (likely this would have helped prevent further complications she had in the coming weeks afterwards) whilst also [redacted] receiving the care she needed.

68. I was probably unusual in that, as part of the Family Council, I had actually been able to see what the new facilities would be like. In a way, this probably made the impact of the delay even worse, because I actually knew what [redacted], and we as a family, were missing out on, yet I had no idea how long we would be delayed at the old hospital.

69. The uncertainty about the delays and the lack of communication also left and me feeling really vulnerable. [redacted]'s treatment and wellbeing was our number

one priority, yet we had no idea when she would be able to benefit from the much improved surroundings and facilities that would be available at the new hospital. We were powerless to do anything about it and this just added to the frustrations and our own worries about what was going on.

70. I should say that we get support at home from the NHS Outreach Service, with having daily one to one support from Band 4 health care assistants. This helps cover [redacted]'s needs in the morning and at night. Her condition qualifies her for the Lothian Exceptional Needs Support (LENS) Panel and this help is invaluable.

COMPLAINTS

71. We did not raise any complaints about the delays. We did consider complaining about [redacted]'s medical treatment when she was in the Glasgow hospital but we had other stuff to focus on (including multiple admissions to intensive care that year) and we didn't follow this up.

REPRESENTATIVE GROUPS

72. I have mentioned that I am part of the Family Council. The Council is basically a group of parents who try to act as a voice for families who are undergoing treatment at the Edinburgh Sick Kids hospital. There are always ups and downs with the families' experiences and the Council is a supportive platform and can raise issues with the hospital management. It's not supposed to simply be a complaints platform. It is intended to be constructive and to be there for families when needed.

73. I felt quite disheartened that the Council was as in the dark about the delay to the move as everyone else. It made me doubt my role and the role of the Council and I wondered if it was an indication that the authorities didn't take us seriously in terms of the work that we do.

74. I think that communication and engagement with the Family Council has improved. I was quite closely involved in the Council's page on the Board's website and this has increased our visibility and made people want to help us. It sometimes felt like the Council's work wasn't appreciated but this is getting better now. There is still much that could be improved further though.

CONCLUDING COMMENTS

75. As a father and as a family, from our point of view, we feel happy that we are now in the new place, because it's got really good state of the art healthcare machinery to give kids the best treatment. They've also got state of the art nursing, with the consultants and doctors too, who look after the whole thing.

76. It's just such a pity that there was such a long delay in getting the new place opened. If people had been kept in touch with what was going on, the plans, the reasons for the delay and how long it would be and how things were progressing, I think they would have been more likely to accept the situation. But there was none of this. I don't blame the medical staff because, like the families, they were trying to make the best of a bad job. I still don't understand why the communication was so bad and I hope that the Inquiry can get to the bottom of that.

77. 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.