Scottish Hospitals Inquiry

Witness Statement of

Andrew Stirrat

WITNESS DETAILS

1. My name is Andrew Stirrat. I was born on [redacted]. I am [redacted] years old. [redacted].

2. I am the father of [redacted]. [redacted]'s date of birth [redacted]. He is 5 years old.

3. I live with my wife, Karen Stirrat, and my three children, [redacted], [redacted] and [redacted], in [redacted], [redacted].

OVERVIEW

4. My son is [redacted]. He was diagnosed with Atypical Teratoid Rhabdoid Tumour (ATRT) in February 2019 when he was 3 years old. [redacted] was treated in the Queen Elizabeth University Hospital (QEUH) from February 2019 and is still undergoing treatment presently. He attended the hospital as an inpatient and as an outpatient regularly for over two years. [redacted] still attends the QEUH for check-ups. I have prepared and provided the Inquiry with a timeline, that my solicitor helped to create, showing the dates on which [redacted] attended hospital and the wards where he was treated. The timeline is attached to this statement (**AS/01**) and I confirm that it is accurate to the best of my recollection.

5. [redacted] spent time in wards 3A, and 3C in the RHC. He also spent time in ward 6A and another ward which is an overflow for ward 6A in the QEUH that he would sometimes get one of his treatments in but I can't remember the number of it. I remember it had isolation rooms though. Ward 6A is part of the new Schiehallion Unit after it moved to the adult hospital. The Schiehallion Unit in the RHC wasn't open when [redacted] was going through his treatment. I

stayed with [redacted] during most of his admissions to hospital as an in-patient and out-patient however, we had [redacted]'s sisters to look after too. I looked after [redacted] most of the time.

6. There are some specific events that I would like to mention. [redacted] contracted an infection in March 2019 shortly after being admitted as an in-patient to ward 6A. There were issues with the water supply during [redacted]'s time at the hospital. I believe that [redacted] was prescribed preventative antibiotics in 2019 which may have been connected to issues with the water supply. In June 2020 the hospital Board decided that [redacted] could not receive surgery and trial medication, due to the costs. We had to appeal this and had the decision overturned.

FAMILY BACKGROUND

7. I live with my wife Karen and our three children in [redacted]. The children are triplets and they are 5 years old. They were born at 27 weeks in the neo natal Queen Elizabeth University Hospital. They stayed in hospital for the first 17 weeks after they were born. Karen was with them during the day as I was working a lot of the time.

8. Before the diagnosis, [redacted] was very boisterous, very outgoing, nothing fazed him. His personality had started to develop. He had no fear, he would give everything a go. He was very friendly towards people, and anybody he didn't know, he would go and say hello to them. Because they are triplets they're like a close-knit community, they've got this sort of 'thing'.
But that was before the diagnosis. That sort of side will start to come back again. When [redacted] had the treatment he just became a different person altogether. He became very reclusive, as it were. He didn't want to associate with anybody outside, and especially when he went to the hospital for visits, he just wouldn't talk to anybody, he wouldn't acknowledge them. He disappeared into himself, put a barrier up to sort of protect himself. And that was him, every time he goes into the hospital now, he just won't talk to anyone.

9. During [redacted]'s treatment, and this included him going to America, if his sisters weren't there, I think it would have been a completely different scenario we would be in just now. His sisters kept him normal, they still treated him as their brother, and they still had the banter, all running about, and it allowed him to still be a child, rather than somebody going through all this really invasive treatment. They just kept it normal for him. If it wasn't for them, he'd be in a completely different place. [redacted] has always got this attitude of, nothing is going to faze me, nothing is going to get me down. If the girls weren't there and trying to keep it normal for him, I don't know if he would have that attitude or if he'd have that fighting spirit. [redacted] was always, I want to go out, and play with his sisters, or go and do this, there's always that sort of drive, there. So if they weren't part of the family unit, sort of thing, I dread to think of what could have happened, or where we could be.

10. [redacted]'s got a close bond with the girls. He and [redacted] are just two peas in a pod, they're very similar. He and [redacted] started to pair up, and hang about together. And so, yes, they're very close.

11. [redacted] has always wanted to play football. Because of the experience he's had, he's not been allowed to participate in all that, in case he gets a knock, however, we just found out that it was actually okay for him to start attending clubs if he wants to go. So that's made his day, that he can go out and join a team, and kick a ball about. Interest wise, he likes YouTube, videos and things and games, he likes playing a lot of games, board games, things like that.

12. [redacted] is starting [redacted] school in August this year. He already has some friends there as he went to the nursery here too.

SEQUENCE OF EVENTS: THE FAMILY’S EXPERIENCE AT QEUH

Admission to hospital: February 2019

13. [redacted] was diagnosed with ATRT in February 2019, when he was 3 years old. He'd been at soft-play, and he'd banged his head. It wasn’t anything major, but I think this is what triggered a response. He started being constantly sick for nearly 24 hours and then he started complaining of headaches. We contacted the local GP and we were told it was viral. Three days later [redacted] was really screaming in pain because of the headaches. By that point, the vomiting had sort of stopped. I phoned emergency A&E and was told again it was viral and to give him paracetamol and ibuprofen, to alleviate the pain. On the Friday, which was 22 February 2019, I took [redacted] to A&E. The doctor came in and assessed him and said, it's viral, sent us home, with ibuprofen, again. The next day [redacted] was still screaming in pain. On the Sunday, Karen took him to A&E again, and they said once again that it was viral. Karen stood her ground and said, no, this isn't right, something is not right here, so they gave him a scan. They came back and said there was a mass and within 12 hours of first going in [redacted] had a craniotomy.

14. [redacted] stayed in ICU for three days and then he was transferred to ward 3A in the RHC. Two weeks later the biopsy came back, and we were told what it was. We were just told it was a mass and that it was ATRT. The Doctors went into detail a wee bit on how aggressive it was, because we didn’t know anything about that at the time. ATRT can grow from a single cell to a huge mass in just a couple of weeks. And that was really it, we went with the diagnosis, we were told that he would have a slim to none chance of surviving as it would haemorrhage.

Experience on ward 3A: late February to early March 2019

15. [redacted] was transferred to ward 3A. I think that’s a post-op ward. While he was there, he loved it because they had facilities there for children. They had a sensory room which he could go into. There were facilities there for the parents, facilities there for the children. If he had been older he could have asked for a DVD player, and a telly, to watch a film. If he had been older, that facility was there for him. Compared with ward 6A, it was night and day.

16. In the sensory room, kids could relate to different things. They would have a globe with lights on it, a fibre optic cable that had coloured lights that come through it, a floor mat with stars on it, and the moon which had LEDs in it as well. There were soft, foam furnishings like a soft-play, like the shapes they could climb up and over, and balls they could play with, just a lot of stuff like that. They had a mirror, lights, and things like that in there. I don't know if it was just because of the type of surgery [redacted] was having, or to make sure his cognition was still there, and if he had any balance issues, or if he fell, you knew he wasn’t going to hurt himself, because it was padded.

17. For parents, they had a kitchen area, a chill out area, so that you could go away and be out the ward. You could sit with other parents and talk about what things were going on with you, and what things were going on with them, just be able to have an adult conversation, rather than be round about a sick child all the time. When [redacted] was sleeping, you could go away and get a cup of tea or a cup of coffee. It was just a nice area to be in, and if any time he was hungry out with dinner time, you could go in there and get a slice of bread, or a wee bit of toast, or something like that, and give him that yourself.

18. There was a microwave if you had food in with you, and there was a fridge so you could bring chilled stuff in and keep it. There was a seating area, like a chill out area, and a cooking area. There was also a wee lounge with a telly in it.

19. Any overnights, I tended to do. There was a pull-down single bed, for parents staying overnight with a built-in system so it didn’t hinder the space in the

room, there was a built-in wall mount storage area, so that when the bed went up it was out the way. Whereas, when he went across to 6A, none of that was catered for, because it was an adult hospital, so all the beds had fold-up camping beds, which were, not the comfiest, some of them would be a lot older than what they were intended to be used for. The bed in 3A was a lot better.

20. There was a TV in all the rooms, I think they try and have a telly on the mount in the room. And I think the one in [redacted]'s room worked. That was one of the fewer rooms where I think the telly worked. When you went into the adult hospital, even the staff said 80 percent of the tellies in the adult ward didn't work, and if you got one that worked, you should count yourself lucky.

21. When [redacted] was in the hospital, he had a nasogastric (NG) tube fitted, for feeding. On 6 March 2019, he had the Hickman line, or central line, fitted for his medication, so it might well have been at that time. I don't recall going in to get the central line put in, before he was discharged but we took him back up to the surgical ward for the surgery under general anaesthetic. He came back from getting the Hickman line done, and they showed us how to change the plaster on it, so you can do it yourself with the Hickman. He was then admitted to ward 6A.

Experience of ward 6A: early March to April 2019

22. Ward 6A is in the adult hospital. We were told by the Doctors at the time, it would be the Schiehallion, the kids' ward, that [redacted] would be going in to. We didn't know until we arrived that the Schiehallion was in the adult's hospital at that point. I think the kids had just been moved out of that into 6A. I don't know if they believed at that time it was just going to be for a short term move, and that's why they described the Schiehallion Ward in the children's hospital as, "It's this fun place to be", and it was all geared for you. I don't know if they knew at that point that the ward was going to be a long term closure. They were still describing that they were only going to be in 6A for a week or two, and then we'd move back across to the other hospital. The harsh reality is that

ward was shut for a lot longer. [redacted] spent most of his time in ward 6A, it's been a hard time.

23. When we first came into the room on ward 6A in 2019, there were two doctors, there. We only found out about [redacted] having cancer, because, one of the doctors said, “We’ll move the chair around so that the oncologist can sit down”. As soon as they mentioned, oncologist, you know that’s actually the road you're going to be doing down. And at that point, that’s when we were introduced – this is Doctor Sastry. So we'd already starting reacting, because they'd mentioned the word, oncologist, and that was us. That was our wee balloon of hopefulness burst. And then, it was straight into the facts of the protocol.

24. When we were first introduced to Doctor Sastry, that’s when we were painted a nice, warm picture about ward 6A where [redacted] was going to get treated in. Dr Sastry was [redacted]’s oncologist. We were told it was the Schiehallion ward we were going and it would be very child orientated, had games rooms, and would never have to feel out of place. There were decorations, and things like that, all for children, it was all for him, and it'll be a wonderful place, and you won't have any worries when you go there. That’s what we were told. I think [redacted] was there when we had to go to ward 6A. I think it was Doctor Sastry or Karen, [redacted]’s mum that told [redacted] directly. Dr Sastry said, it's a wonderful place, nothing to worry about, it's all for you.

25. [redacted] wouldn’t talk to anybody. Because of the different faces, he just never had a rapport with them. He never spoke to Doctor Sastry. I don't know if it was just Doctor Sastry’s bedside manner, but he just didn’t have that connection with [redacted].

26. In March 2019, [redacted] went into ward 6A, and you’ve got a three year old asking you, where’s all the pictures, where’s all the toys, where’s the special room, or the sensory room, all that stuff. You're walking into a ward that has nothing in it, it's a grey room, and they'd stencilled on a wee picture of an owl,

or something like that, onto the wall, and that's the extent of the decorations for children in the place. There was an owl in one room, and you go into another room and it's maybe a fox, or a woodland creature. There's no games area at all, there's nothing for children. We asked where the play area was and were told there were two tables with four chairs, when you walk into the main ward, sitting in the corridor. It had some colouring pencils, and a couple of sheets of paper, and that's it, that's the extent of it.

27. It was like, at the last minute, they've arranged this ward. There's been no planning there for transferring people across. So when you come in the main door of ward 6A, you were greeted by long term rooms. You would first walk in the double doors, I think, there was an aqua therapy room in the first door when you come in. The aqua therapy room had a hydro-bath in it. We had never used it but I asked one of the nurses or auxiliaries about it and they said it was out of use as the filters for the water couldn't be attached to it. It was never used the whole time we attended the QEUH with [redacted].

28. You would go into the rooms and they had all the filters for the water system. These were white plastic filters that clamped on to the taps of the sink in the room and the one in the bathroom. As you passed through the ward, you had the two tables and chairs sitting on the right-hand side, next to the window. You would go through another set of doors, and there would be a nurse station on the right-hand side, and there'd be like a sort of general area for the boards, so it would tell you who was in the rooms, and who's getting what, and who's their Doctor. Continuing down that corridor, there were more residential, long term stays on the left-hand side. You would get to the kitchen area in the ward, but no parent was allowed in, it was for staff only. If you wanted something out of that, you had to ask a member of staff to go and get it for you.

29. When you're going through the ward, you go through another set of doors, and you get some more rooms for long term patients, and then you had a double door at the end, that was the day-care room. Day-care was for patients

that were coming in for a check-up, or they had to receive new medications, or any equipment, or to go in and get chemo that didn’t require to be an overnight stay.

30. You had all the long term care, and everybody that was coming in, every Tom, Dick and Harry walking in, in the winter and summer, walking through the ward, past kids that might be playing at the table and chairs. These kids, and the long term patients have all got very low immune systems, and you’ve got everyone walking by, coughing and spluttering, walking by all these rooms to get to day-care or the medication room. I thought, why not have day-care where the nurses station was and keep the general flow of people away from the long term ones. A lot of the room doors would be shut, but a nurse or Doctor would be going in and out of the rooms and be leaving it wide open. It's just insane, to know that you've got all these people that are very neutropenic, with very low immune systems, and everybody has to walk past their room to get to the day-care clinic. I just don't know why they thought that would be a good set-up.

31. In the late afternoon and early evening, the rooms going down the left-hand side were the ones that caught the sun. Those rooms were particularly warm all the time during the summer. There was no way of regulating heat in there, because of the air conditioning system through the hospital was centrally processed. If you asked for it to go down, it wouldn’t make any change in the room, because all the rooms had to be changed on that side, down to the same level, for there to be an actual drop in the temperature. The rooms had blinds incorporated into the windows but a lot of the blinds didn’t work. If your room was lucky enough to have a blind that worked, it cut a wee bit of sun out.

32. It was a very warm side of the hospital. They would try and do temperature checks, you're sitting in a room, and it feels as if it's about 26, 28 degrees. I wouldn’t even be in a bed, and I’d be sweating. You could feel the heat in the room. I can remember them doing temperature checks and saying, “Oh he's

fighting a temperature”, and I’d wonder what they meant. Rather than check his temperature and wait a couple of hours, and then come back and check it again, it was just like, “He's fighting a temperature, oh that’s him, he's in isolation”. I’d be thinking to myself, is this medically related, is it a bug? Half the time, it was just the temperature in the room, it was just so hot.

33. On one occasion, I asked one of the nurses to turn the temperature down. That’s when we were told it was centrally controlled. That’s what they'd been told to tell us – no, we can't regulate it ourselves. During the height of summer, a staff member told us you’re meant to keep the room shut all the time. I think this was to stop the spread of diseases through the ward if anyone was isolating. We had just been trying to keep the rooms open to let air circulate but this wasn’t allowed. There was an air filter in the room and I believe that if the door was left open, the filter didn’t work properly or circulate the air the way it was supposed to.

34. The temperature was centrally processed so if you put the temperature down, it could only go down between the range on it was between, I think, 19 to 23 degrees, so there wasn’t a large range. If it was sitting at 23, and you put it down to 19, you didn’t really feel a difference, because you couldn’t turn it on cold. There was nothing to drop it all the way down and then you’ve got the heat coming in from the sun. That side was really hot and it was the exact opposite on the other side. When [redacted] first went in, it was cold at night and I was asking for four blankets, I was freezing in there. [redacted] had a couple of blankets on as well, just to stay warm. I brought a sleeping bag because it was easier. I always felt I didn’t want to harass the staff for bed linen, and things like that, at night because I thought they had enough to do. Plus, depending who it was that came in on the night shift, you got the impression that quite a few of them didn’t want to get you a blanket as they had other things better to do.

35. In the room you just had a fold-out camp bed which hindered the space you had. It wasn’t always folded up, so you had that taking up a section of the

room. There was no standard size of rooms on the ward, there were smaller rooms and larger rooms, depending where it was. Once you put that bed in, and a chair, there was very little floor space. At one point we asked to take [redacted] out the bed. The staff said we could walk around the ward but we would need a battery pack with the IV lines. You'd be lucky if you could get one of them that worked because the battery packs didn't hold a charge very well.

36. The battery packs were for the IV line, or the IV unit. Generally, they're plugged into the wall, and they're meant to have a battery pack in the unit, so that if there was a power outage or anything like that, the IV line would stop working, and it would continue to work. If you were moving between rooms, or having to be transferred between wards, the IV line would go with you, and you wouldn’t have to try and get disconnected. If you were an older child getting chemotherapy, you'd be able to go to the toilet with it, without having to get disconnected all the time. The battery pack units very seldom worked, so when you were in bed, you were stuck there, you couldn’t leave the facilities, or you couldn’t leave the room, to go for a walk, or even just leave the bed area. I know [redacted], at some points, had two of these IV units, or two poles with several IV units on each pole.

37. [redacted] had a four headed pole with medications and three IV fluid packs on it, as well as another stand which would have maybe some more pain relief, or things like that. He would have all these, and on his Hickman line, he had two ports on it. Both of them might be connected, there might be additional fluids there for when the doxorubicin, and when it ran out, they could just link the IV line straight to it, so it started to flush it out his system. He could be sitting there with two IV poles with no battery in it. If you maybe had four of these pumps on it, you could have four batteries, and nine times out of ten they wouldn’t work. So you couldn’t take him out, he couldn’t move about the room freely, you couldn’t leave the room to go and play in the so-called play area that was along the hall.

38. If I asked about the battery packs, I was told it was an ongoing thing, they'll get round to it, sort of thing. That was what the staff were getting told, they'd put in the request about the battery packs, and that's what they got told. As far as I'm aware, it was maintenance that the nurses were putting the requests in to. The battery packs for IV drips were used through-out the hospital and each ward had someone allocated to them. The machines were coded per ward so they knew where they belonged.

39. We asked about getting a floor mat, or a mat for [redacted] to play on in the room, and again, there wasn't enough of them either. Several times we asked and we were told there was none. They didn't like you knowing about where the mats were kept, because they didn't really want the mats on the floor. That was the impression we got, they didn't want the mats down, because if they were coming in to do a cleaning, and things like that, the mat was in the road. Nine times out of ten, they wouldn't have a mat for him to play on the floor, because they didn't want the mats down. Andy, one of the auxiliaries, told us where they kept them, in the storage area, which was the aqua therapy room. That was the storage area for the play mats.

40. There would be two members of staff that would give any medication to make sure it was given correctly. Nine times out of ten, the nurses themselves would not administer that medication, unless it was chemo medication. Any other medications were left for the parent to administer themselves. When [redacted] had anything that had to be given orally, like his Posaconazole, and his ondansetron, which is an anti-sickness medication, we would be left to deal with that. On numerous occasions the night shift staff would give out the medication for the morning dose but the night shift finished at about seven, and they never told you that it was there. On one or two occasions, there was medication sitting, but it was hidden by a packet of wipes, or other bits and pieces lying about. As you were doing your tidy-up or things like that, you're finding it, but nobody was letting you know they'd been sitting there.

41. The nurses there are overworked as it is, they've got a lot on their plate, and they're answering calls to go and get a bottle of water, or a cup of dilute, or something like that, or whatever you could get. They never had a large supply of food. The children might have the odd yoghurt, or sandwiches, things like that, but there wasn't a general good supply of everything. Kids on chemo, just like anyone on chemo, their sense of taste changes, and their sense of smell, so a lot of the food was awful, especially for [redacted]. He wouldn't touch it; he just wouldn't eat anything. He just said, it didn't taste right, or it tasted awful.

42. Sometimes, the catering staff wouldn't give you the right menu, or you would have stuff that was missing. On several occasions, when [redacted] was in to get a transfusion done, nobody had come in to see [redacted].[redacted]had gone in at eight or nine o'clock in the morning, and come seven or eight o'clock at night, nobody from catering had come in to see if he wanted something to eat. At that point you have to leave him on his own, you have to try and get something to eat. He'd been in for 12 hours and nobody had come in to see if he wanted a sandwich, or a cup of tea. I would say this probably happened 50 per cent of the time. When you did see catering staff and asked for stuff the dietician and the catering manager told us was available, the staff wouldn't accept your word for it and would give you the same two options.

43. There were activity coordinators who would come in every so often, but [redacted] was very reclusive at that point, he didn't want anything to do with anything. They'd bring in maybe a toy, or something he could play with himself, like a box of Lego, or something like that. But there was nothing, really, for any children to use, whereas older children were quite happy to sit down and watch the TV, or the person would bring in tablets for them to use. Before [redacted] was diagnosed, we weren't going down that route of giving iPads, and all that stuff, because we didn't want him to be associated solely with YouTube at that age, and we would want him to use it later on as a teaching aid for his studying, and things like that. So we never intended giving any of the kids anything like that at such a young age.

[redacted]’s treatment in Florida: April to June 2019

44. The hospital paid for [redacted] to go to America for proton beam therapy as at that point it was only available over there. Proton beam therapy is less invasive to healthy brain tissue whereas the standard radiation therapy, like you would get at the Beatson, is more damaging to healthy cells. The analogy that was given to us at the time was that the proton beam is like a sniper rifle so it’s focused on just a certain point and damages only the cells it’s targeted at and the general radiation is artillery so it obliterates everything. It was planned that it was just going to be me and him that was going. They then said they thought it would be too much for one person to travel and have to be with [redacted] all the time. Not that that was a bad thing, but whoever went, it gave the person no respite and time away from the situation. They asked us about another parent going, or somebody else going, to split the workload and said that both parents could go. We didn’t think it would be good that we left the girls behind, because it's a long period of time to be away from their parents and their sibling so we paid the difference for the girls to go. There was also the fact that if both of us had to attend a meeting, somebody would have to be there to look after the girls, so we took, and paid for, Karen’s mum and dad to come as well, so there was seven of us going. Karen’s mum and dad looked after the girls while we were having anything to do with the chemotherapy, or the proton therapy.

45. We left to go to America just after Easter on 22 April 2019, but we were supposed to leave two weeks before that. [redacted]'s neutrophil level just wasn’t recovering the way it should. He had an injection in the leg, which was an artificial dose for his immune system, to try and help it recover. I was shown how to give [redacted] this at home to save him going in to hospital but I wasn’t comfortable doing it. He used to scream, “Daddy, don’t hurt me”. He had an IV line of the treatment and then an injection rather than having two injections. At one point though, staff were getting ready to give [redacted] the two injections back to back. There’s supposed to a large gap in between the injections but because [redacted] was due to go on a flight, they had to consider the option of

the two injections being given rapidly to try and get his levels up but his body reacted before they had to resort to that.

46. In Florida, we had a meeting with the oncology team in Jacksonville. Our main point of reference was the Oncologist, who was from the proton beam team. He asked us why [redacted] was on posaconazole and we said we were told it was part of his chemo protocol. He told us it wasn't so we asked him what it was used for. He said that the hospital is dirty, but it might also be to do with the climate, which is a damp climate, which gives rise to infection. The main reason for the posaconazole, as far as we can tell from what was said to us, is that the hospital is dirty, it has contaminated water, and that's what we were told by the Oncologist. While we were there, he told us to take [redacted] off the posaconazole, for the full stay in Florida.

47. [redacted] never had posaconazole while we were there, at all, and he was great for it, he was running about all over the place. He had his daily radiation therapy five days a week, and he had weekends off. He was in for the morning; come lunchtime he was out. He was still lethargic, but he was still getting the chemo once a week. He never had to use the posaconazole again while we were in America. However, when we were getting ready to come home, they told us, as soon as he got on the plane, to give him the posaconazole so it was back in his system again, when he went back to Glasgow. This was because he was going back into the hospital environment at the QEUH.

Admissions as in-patient and out-patient: Ward 6A - June to December 2019

48. We got back to Glasgow on 21 June 2019. [redacted] went back into ward 6A where he received more chemotherapy. He was an out-patient for this although the chemotherapy would maybe be done over a couple of nights. [redacted] got to go home after his chemotherapy and was only ever kept in if he had an infection, or a spike of temperature, which would be classed as infectious and then he wasn't allowed to leave because he'd pose a risk to himself and others. We were never told about any specific infections but if he

presented with a temperature, [redacted] would be kept in hospital. Nurses would come in to check his obs and carry out temperature checks. As far as medication goes, I don't think there was anything extra given to [redacted] but I can't recall exactly. His immune system just wasn't really repelling anything, he would get the best care in the hospital rather than trying to come home and then come back in again for his temperature, when it went over 40. I don't remember how many occasions he was in and out between June and December but [redacted] was an in-patient for approximately four to five weeks. This was before we went to America for his Proton Beam Therapy.

49. My aunty came up to the hospital after she finished work, to help and to visit so that I could get away from the room for a wee while. She did that quite a bit, but I can't remember when it was. During the time when [redacted] was an in-patient for four or five weeks, I think he left the bed, three to four times because we couldn't get the battery packs to move about with. As a result of that, his muscles had started to waste in his legs, so they had physio in for that, because he couldn't leave the bed to move about. It was a good while before he managed to get home, but he was only home for maybe a couple of days, and then he was back for the next bout of treatment anyway.

50. The dietician had told us there was plenty of food there for [redacted] and different menus and if we asked for them we would get something on those menus for [redacted]. In ward 6A, there were no food facilities for the children themselves to store anything so you were reliant on staff providing meals. We fought that. When we came back from America, we were told by Angela, the staff nurse, that we had been given a bit of space in the fridge so we could bring in chilled yoghurts for [redacted]. He went through a phase of cucumber sticks and fresh strawberries, which he couldn't get from the hospital. They allowed us to bring a packed lunch in, so we could store it in the actual ward. Then we were told not to tell any other parents that we were getting this. It was like a bit of preferential treatment, which we didn't think was right, and obviously we didn't keep that quiet, because why should [redacted] get things above other parents who are going through the exact same thing. I think it

probably stems from the fact that, the local paper in our area had always talked about [redacted], and they liked the updates. I think it had appeared in one of the local papers, that they weren't willing to give him this stuff, and that we stood up for kids' rights, and our rights as parents, that sort of thing.

51. Nine times out of ten it was an overnight stay when going back into the hospital for chemo. The medication he had was vincristine, and the other one was called ICE. Here, in Britain, you got ICE over a period of time, and a flush afterwards. It was an overnight stay. In America, that treatment is approximately two to three hours. So you had that variation in treatment but I don't know which one was better. It meant having to stay in a hospital that wasn't clean, so you were always worried, because [redacted] had the central line as well.

Completion of [redacted]'s treatment: November 2019

52. I think [redacted] finished his treatment at the end of November 2019 and that's when his hair started growing back in. When we came back from America, they took him off the posaconazole, and they gave him ciprofloxacin, I think it's another anti-fungal medication. We researched that one, and for adults at the time, they recommended they should only be on it for two weeks, maximum. The dose [redacted] was on was for four months, and when we started to push for when he was going to come off it, after the meeting the Health Board had with the parents in November 2019, we were told that he was scheduled in to get his line removed a week later instead of the original time which was the week before Christmas. [redacted]'s treatment had finished in October/November 2019 so Karen had asked why his line was being kept in as it meant he was on this medication for longer. It felt like, as if the hospital didn't want to answer any questions Karen asked in regards to that, they just went in and [redacted] had the line removed. They had to wait and make sure there wasn't anything else they could follow up; he had to have a scan done to make sure nothing else had grown before they could remove the line in case more treatment was needed. They also carried out weekly tests on the

line. [redacted] then had his line removed earlier than originally planned. It was another general anaesthetic when that was removed. For every procedure, and any operation that [redacted] had, he always got a general anaesthetic, including the proton beam radiation therapy, and at the Beatson, which I will come on to. I think at the moment he might be sitting at 110 general anaesthetics he's had in the last year, so it's quite a few.

[redacted]’s Relapse: May 2020

53. [redacted]’s chemo finished in 2019. He had a grace period between the scans. He had the first scan after the treatment finished, which he was okay with, and then there was another scan planned for April 2020, but it was delayed because of the Covid pandemic. We waited for a month until May. We spoke to Doctor Sastry at this time, because he'd been really good to talk to in regards to the treatment. He fought for [redacted], in a lot of aspects. We asked him why the scan had been delayed. He told us that out of all the scans he does, he had 50 kids that he wanted to get scans for, but he was told that out of that list of 50 names, he had to cut it down to five that needed it more than anything else. Dr Sastry unfortunately had to cut the list down to five. He then approached the Board and said, this is the five names I've got, and then he's been told to cut it down to three. He stated [redacted] was always at the top of the list in regards to that. He's then gone back with his list of two or three names, been told to cut it down to one. At that point he said, no, I'm not doing it anymore. It's as if the Board didn’t want to do the scan at all. [redacted]’s always been on Dr Sastry’s list because of how quickly his disease grows, because it can grow from a single cell to a huge mass in a couple of weeks. It's very, very aggressive, very, very fast-growing.

54. We got told this over the phone, or when [redacted] had one of the clinics, I can't recall exactly when it was, but that’s how we were told by the staff. I think it might have been after getting the scan, when we were told that he'd relapsed. At that point, we knew that we had to come back in and they asked us to take [redacted] in with us. We found that strange, but we took him anyway. I got a phone call at nine o’clock in the morning, from Angela the staff nurse, asking

for us to come in at half past 12 that day, for an urgent meeting. The fact that [redacted] had a scan the previous week, and then we were getting told to come in, rather than waiting a couple of days to get the scan result, you knew right away from the urgency of them reacting to that, something wasn't right.

55. The meeting was on 1 June 2020. [redacted]'s surgeon, Roddy O'Kane and Doctor Sastry were there. Angela, the staff nurse was also there, I can't remember her second name. That's when Doctor Sastry said that the scan showed that another mass had grown in his head. [redacted] had relapsed and he'd got four to 15 months to live. He told us to go home with him, there was nothing they could do, there was nothing in place. When we asked about the radiation therapy from the Beatson, we were told that wasn't available to us. We asked Roddy directly what the chances were of doing surgery, but he was very vague. His body language was off, he wouldn't look us in the eye, and he was distant. We asked why they wanted us to bring [redacted] in at that time, watching his parents break down. We were told by Doctor Sastry, that if we went and found a treatment that he could use, then they would take it from there. They offered no alternatives, there was no backup solutions. They gave us no aftercare or responses or anything like that, to deal with getting news like that. There was nothing there to help us deal with that sort of information. You were basically given that news, and told, bye, bye, see you later, let us know if you have any questions. There was no counselling, or anything like that.

56. After the initial shock wore off after a couple of days, Karen phoned Roddy directly. As it turned out, at 12 o'clock on that Monday 1 June 2020, they had a meeting and discussed all their current cases that they're dealing with. Roddy told her the plan was that he had asked us to bring [redacted] up, because he had previously planned on taking [redacted] in for surgery and was going to tell us at that meeting, but he was then instructed by the Board, and the oncology team, that he wasn't to do that, because there was no oncology protocol in place for [redacted], to back up the surgical side of it.

57. There was a lot going on after that, trying to get the treatment in place for [redacted]. On the Friday after, between 5 June and roughly a week later, it was a very hectic time, a very busy time. Karen phoned[redacted]in Jacksonville, and spoke to the chemo team there. They put her in contact with the clinical lead in Manchester, who were using a drug, the drug [redacted]'s on just now. Karen spoke to the clinical lead in Manchester. It turned out the clinical lead in Manchester is best friends with Roddy, because they trained together. He told Karen it was a pity we didn't live near Manchester, because they could have got [redacted] on this drug, almost immediately. Our response to that was that we could have been there in a couple of hours. We would have done anything for the boy, that wasn't an issue. He told Karen that because we had a neurosurgeon on our side, [redacted] was best staying where he was and they could liaise with them and the oncology team. We passed that information on to Doctor Sastry, and it seemed as if he was dragging his heels on that. He was saying, he had to get all these different rules and regulations between NHS Scotland and NHS England, or he was waiting for paperwork in regards to that, in regards to the drug as well. It turned out, the clinical lead sent all that off so it was Doctor Sastry, himself, he was just dragging his heels, and didn't want to go down that route.

58. We later found out that it's up to a Board to decide what trials they're going to be using. You'd have five doctors who are the head of their field in that regard. Out of the five, there was always one that said no to every trial. What we've been told was, it was Doctor Sastry who was the nay-sayer, he was the one who would reject everything. Doctor Sastry hinted at something: he went out of his way to get something done and it didn't work out, so he didn't believe in trials, those were his words – "I don't believe in trials". I don't know why he said it but he didn't give us alternative options.

Surgery and admission to ward 3A: June 2020

59. We fought for [redacted] to get onto the drug eventually, and because we got an oncology backup to the surgery, the surgery was put into place so that [redacted] could get it. We were then contacted by the Beatson and told they had

a course of radiation therapy available to [redacted] as well, because we had got an oncology drug to follow up the surgery. We went from having nothing to having every door opened up and they were saying, “Oh, we can do this now”.

60. The diagnosis to address the relapse was on 1 June, so it was between 14 and 21 June 2020, that the surgery took place but I don’t know the exact date. The surgical ward is 3A, or 3B, something like that. Roddy had wanted his full surgical team in and had been hoping [redacted]’s mass wouldn’t cause any other brain haemorrhage but due to Covid, he couldn’t get his full team in any sooner. Thankfully [redacted] made it until the day the surgery could take place.

61. The surgery involved [redacted] having another craniotomy resection, which is when they discover a mass within the brain cavity, or in the skull cavity within the brain structure. They make an incision, generally behind the ear, depending on where it is, but in [redacted]'s case, it was behind the ear. That incision went almost to his other ear. That was so they could pull the skin back, and expose the bone of the skull. With [redacted]'s first resection, the mass was on his right frontal lobe, so it was on the front half of his head. They made an incision at the back and across, so that they could take a section of his skull out, and access in the brain area where the mass was, and remove it. When he had his second resection, I think they used the same incision point as before. The mass was on the posterior part of the right side of his head. When he had the first surgery, the frontal lobe one, he had been bruised. That’s full of cerebral fluid, now, there's no brain mass in the right side, the front of the right hand side of his head.

62. When [redacted] went back into hospital for his surgery in June 2020, he had been prescribed morphine to relieve the pain, and we were told the wrong dose from the hospital, on his medical records, the level of morphine that he was getting was three and a half millilitres, every four hours. We were told it was 1.2 mil. We were only giving him that, and the medication was only lasting about half an hour. We didn’t know if we could give him anymore, and

when we queried it we were told, no just give him what was on the bottle, and what was on the bottle was 1.2, and not the updated amount of 3.5 millilitres.

63. The proton beam therapy [redacted] had in April 2019 was focused on a certain area and only damaged the cells it was directly targeted at, and it had what was called a dispersion field. When the protons went into the targeted area, with the dispersion field, the proton beams didn’t kill one of the cells. The cell was hit by the proton beam, but it was under this bed in the dispersion field, so it wasn’t destroyed. The chemotherapy [redacted] was getting before had previously suppressed the cell from growing, so when [redacted]'s chemotherapy stopped, the cell started growing again, and that’s how he had the second mass. [redacted] then had to have a second session of treatment and the surgeon had to cut away another bit of the skull on the right-hand side, to remove the mass again, and then put the bit of skull back on.

64. Roddy told us that it was one of the top five surgeries he's carried out in his career, in regards to how easy it went. I think the mass itself in [redacted]'s head was close to the brain stem, that’s why Roddy wanted the full team there, to make sure that he didn’t actually hit the brain stem area. He told us the mass was five millimetres away from [redacted]'s brain stem. We assumed this was a concern, but Roddy was very confident. He said five millimetres was a huge gap, he only worried about it when it was one millimetre away from it, because that would have been serious. The surgery was very good. I think they said it would take 18 to 20 hours to do the surgery, and he was in and out in 12.

65. [redacted] just bounced back from it, right after the surgery, within 24 hours. He was off morphine, and within 36 hours he was off all pain relief and was asking for a McDonald’s. They try and keep you in a week before you get discharged for a major thing, and [redacted] was in for five days, because he was walking around and he was eating. It was like seeing a switch going on.

66. Since we raised the issue of the treatment with Dr Sastry, he has been very quiet. It’s as if he had no interest in [redacted] who was is his patient. Any time we

would be in the hospital or on the ward, he would never come in and say hello. If you saw Dr Sastry, it would be through the window in the room and he might look up and in the window so he knew you were there but he would never come in and speak to us or acknowledge us. This happened to a point up until about Christmas with Karen and it came to a head and was resolved. Since then, he's been a lot better and he now makes a point of actually coming in and saying hello when he can, at the times when [redacted] is in the hospital.

67. [redacted] attends at the hospital once a fortnight, unless anything happens. He goes in and gets weighed, gets his bloods done, and he gets checks done because of the medication. He gets a monthly check done to do with the bromide levels in his kidneys, because of the medication. He gets an ECG done also. When he first got prescribed tazemetstat last year, he was never given an ECG so we raised that because Karen's been on a Facebook page with other people that have been using the drug, and there have been parents saying they got an ECG done every month to check and make sure. It's because the drug itself can have an impact on the heart, and the kidney function.

Admission December 2020: Meningitis

68. In December 2020, [redacted] had been complaining of a sore ear, on the right-hand side of his head, where the surgeries had taken place. The medication that [redacted] was on can cause ear infections, so we met with ENT. The ENT doctor looked at his ear and said there was an infection there, however he didn't know if it was going to cause anything. He told us to go home and if it got worse, to come back in. He was aware there was an infection there, and we were sent home, and within a couple of days, [redacted] spiked with a temperature. He was rushed in to the ICU with a temperature of 40 degrees, or something like that, and he'd been over 40 for a couple of days running.

69. At that time, we were told, by one specialist that it had come from the ear infection, but they couldn't tell me what it was because doctors had

bombarded it with antibiotics which had broken the chain. Then, later, a consultant came in and said, no it's nothing to do with the ear infection at all, I don't know what you're talking about. Karen told him what the specialist had said, and then he sort of backtracked, he didn't know what he said, and the consultant left the room at that point. It seems to have been since the meningitis, as if they're trying to protect themselves from that, around the area of competence, to a certain extent. Now, if we have an appointment to go to the ENT, there's always a Doctor, and somebody else in the room with us, there's always a witness in the room, whereas, when we first had conversations, there wasn't anybody.

WATER: EVENTS INVOLVING WATER SYSTEMS

70. When we first went in to the hospital in 2019, I recall seeing a sign above the sink in the main room, and also above the sink in the toilet area in ward 6A. I don't recall seeing these in the RHC. In the main room there was a sign above the tap saying, "Do not drink this water, bottled water will be provided for you". I noticed more recently that the sign has been reworded so it now says, "This is for hand use only", so they've removed the part about not drinking the water. The sign has always said you can't pour other liquid down the sink apart from water. It's a sink, and you can't empty out old juice down it. The bathroom area is the same; you can't pour anything down the drain and you can't clean anything.

71. If you wanted a drink of water you had to get a bottle of water. When the kids were born in 2016, we were told then too that if you wanted water, you couldn't drink the tap water in the wards. If you wanted to drink anything or give kids a drink, it had to be bottled water so even back then, you weren't allowed to drink the tap water.

72. Every so often, I think it was once a week, two workman type guys in overalls would come in and they would pour a cleaning fluid down the sinks. I think it was the janitor staff or the maintenance staff, the staff with the green shirts on. They don't check to see what's going on in the room, they just walk

straight into the room. You could be doing anything in that room, but they don't wait, they just walk in, there's no care about what's going on inside the room. They don't check to see what's going on first, they just come in, they put fluid down, and then they just walk straight back out again. A lot of times, they weren't coming in with masks on or any PPE equipment at all, they just walked straight into the room with their overalls on.

73. All the guys said that came into the rooms was that they had to clean the sinks, that was all, there wasn't any reason, they never said anything like that. I just took it as a sort of maintenance cleaning regime, or something like that. The cleaning staff would come in, it was supposed to be once a day, I think, and sometimes at the weekends they came in twice a day. There were the odd days, where nobody came in to clean anything at all. They were supposed to run the showers in the ward for three to five minutes. A couple of the cleaners did do that, and there were other ones that just didn't run the shower at all. You'd be sitting there chatting away to them, and we'd ask them, are you not meant to turn that shower on, and they'd say the next person would get it. They wouldn't tell you why they were told to do it but apparently it was to stop Legionnaires, the water build-up in the showerheads. I think someone had said to me roughly six months ago or when [redacted] was nearing the end of his treatment for the relapse about the Legionnaires. I can't remember who it was though. Someone on the ward had come down with Legionnaires and as far as I'm aware, you can only get it from water. Nobody had mentioned why they were running them, they just said it was so that you didn't get stale water.

74. There were filters on the water system, the taps. Staff told us it was to keep water at a cleaner level as it was in the Schiehallion Ward and because that had now moved to the adult hospital, they were trying to keep the same level of cleanliness and purity towards the water supply. I think it was a precautionary measure for water issues that had happened with the seagulls and the pigeon droppings, that was in the water supply. At one of the meetings we attended with Jeane Freeman, I think it was a person from

Maintenance that said the pipework had too many dead ends; when it came to a right hand junction in the pipework, rather than being a flush junction, it would be a T-shape. This meant that the top half filled with water but it couldn't go anywhere and would go stale. Every so often there would be a surge of water that cleared it out and it would go into the main pipe system. Anas Sarwar had a report about there being too many dead ends in the pipework and all the contaminated water was getting flushed back out again. From that report, the pipework had been contaminated before when an outside pump station had diesel or pooled water going into the system. I think this was 2015 before the hospital opened. He also told us that the hospital would rather pay out in claims against the hospital than fixing it as it would cost less to pay the claims than it would to fix the pipework. Initially, we weren't told that it was anything to do with that though.

75. I don't think it was the filters that were on at the beginning, are the ones they have on now; I think they found a better way of putting them on. There were no filters on the taps that I can recall in the RHC. The first time they appeared, it was only in ward 6A. If you went to any of the clinic areas down stairs in the RHC, they still had the water stations in the foyer, they still had no filters on all the taps down there. We were told by staff from the clinic that, if at any time, when we were at a clinic, and we needed the toilet, we were to go up to 6A, so that [redacted] wasn't exposed to the unclean water, because the filter system wasn't in place down the stairs at clinics in the RHC or downstairs in the adult hospital either. It wasn't in place anywhere else in the hospital that we had been in, apart from 6A although I believe six to eight months later, they were starting to be installed downstairs.

76. There were filters on the basins and every sink that we had access to in ward 6A. I don't think they had filters on the sinks in the catering area but we weren't allowed access to that area, it was only the taps that were in the rooms. If you wanted anything from it, you had to ask a member of staff, one of the auxiliaries, and they would go and get it for you.

77. When [redacted] was on weekly chemo, I can't remember the exact date, I recall somebody coming in and they said there had been a new team set up to liaise with the patients in regards to what had been going on in the wards, and in regards to all the news coverage that had been going on with the water.

78. Stories were breaking in the papers in regards to water. They were just letting us personally know what was going on, and if any articles that were going to hit the papers the following day in regards to any water scandal, they would come in and talk to the parents about the article. The team that gave us the updates came in a couple of times. There would be an article coming out in the paper the next day, and they would ask if we wanted to have a discussion about it and ask any questions. You never saw them at the beginning, but then when the water thing really did kick off, this team were there to coordinate with parents, but I only met them once or twice. They said they would come in and speak to all parents on a weekly basis but they didn't. I think I met one or two other people, over the space of a six month period, from February 2019, but I can't recall names. The first time I saw one of them would have been round about August/September 2019 when the story about contaminated water appeared in the media. The next time I saw someone, it was when a story had been leaked about the Health Board; someone had come in and told us it was going to be appearing in the press. There was very poor communication on that side of it as they didn't speak to us weekly as promised.

CLEANLINESS

79. A lot of time you would go in to any of the wards and some of the rooms were dirty, they weren't cleaned to a high standard. There was a fine layer of dust along the back of the lights, on the wall-mounted plugs, light switches. A lot of the rooms had facilities so you could hang clothes. The furniture is supposed to be moved on a daily basis for cleaning under it. I can recall on several occasions; it was only one certain member of staff that would do that. Other cleaners would come in, but not move the furniture. They would mop the floor that was generally walked on. If you were sitting on the chair, they wouldn't

ask you to pull the chair out the road. Some of them did do a very thorough job, but there were others that didn't.

80. They used chemicals for cleaning the floors. When they came in cleaning, you would always have a strong smell of a bleach derivative. You always had a strong smell of chlorine when the room was getting cleaned. Sometimes it was so strong, it was catching on like the back of your throat. One weekend, the floor had been cleaned in the morning at 10, or 11 o'clock that day. Later that night, I took a shower in the room area in ward 6A, and I'd put towels down on the floor, and one of them was grey. After taking a shower, I lifted up that towel, and the colour had been stripped out it. That had been a very strong reaction to the bleach. I raised this with the cleaning staff, and I showed them the towel. I asked why chemicals were getting used and why they were so strong and getting put on the floor. In our room in 6A, [redacted] never used the toilet, he was bedridden for long periods of time, and he was in nappies, so he wasn't using the facilities within the room itself. All the rooms were en-suite on that ward.

81. My reason for reacting to that was that there were other older children that have to use the toilet, or if they had a shower, or walking about barefoot in that room but they were walking about in that. If the floor was wet or damp, you've got this strong chemical sitting on the surface. Is that going to cause sores, or damage to the other patients?

82. My concern was that the cleaning staff that had gone in on that day weren't the usual staff you would see about, and they'd used a liquid that looked as if it wasn't diluted. They poured it onto the floor, and it went down as a gel which wasn't watered down. The cleaning supervisor came in and said it wasn't bleach they were using; it was a bleach derivative. They'd been given a chart on how to breakdown the dilution of it, and it was followed to the letter. They were adamant that it had been watered down and diluted.

PHYSICAL EFFECTS

83. A lot of [redacted]'s physical health was to do with the fact that he couldn't leave the bed. He was bedridden for long periods of time, he was having muscle deterioration in his legs, which he's still recovering from to this day. He gets tired quite easily when walking for a distance, so much so that he still has a buggy to be pushed around in. For short distances, he's fine, but if he goes out for the day and he has to do quite a bit of walking, he'll get to a point where his legs are sore. He just doesn't want to walk anymore and you see the energy slowing draining from him. That's still ongoing, where he doesn't have the energy anymore. I think this is because he couldn't leave the room for exercise as there were no battery packs to allow him to do that. He was stuck in his bed most of the time. Even if he did get out of bed, he was still sitting playing and in his room due to the lack of battery packs for his drip.

HEALTHCARE ASSOCIATED INFECTIONS

84. I don't recall which infections [redacted] had. He had a number of infections while he was in hospital. We were never given any information on if it was an infection, or not. We were never given the names or any specifics about any infections [redacted] had but he was kept in whenever he had a temperature spike.

85. There was one incident, I can't recall when it was, they came in and took cultures, and we were told [redacted] was to be put into isolation. Isolation is when the parent stays in the room with the child, and you have minimal contact with anything outside the room. The child is not allowed to leave the room with their parents, it's supposed to be minimal contact but if you're needing anything from the shop, you get a window where you can leave.

86. We asked if he was officially in isolation and one member of staff said, yes, and later on another came in and said we weren't in isolation. At that point we took [redacted] out, and he had a wee walk around the ward. The following day, the original member of staff came back and asked why we didn't have an isolation sticker on the door, and that we were in isolation. It was as if the left hand didn't know what the right hand was doing. One person was telling you one thing, and another person was telling you something completely different.

PREVENTATIVE MEDICATION

87. [redacted] was on daily medication that wasn't part of the chemo. These were ondansetron, posaconazole and ciprofloxacin. [redacted] was on posaconazole from the moment he was first diagnosed which was February 2019, when he had the central line put in, until he came back from America, and then at that point it changed to ciprofloxacin. We weren't told why he was put onto that, we were just told to put him on it and take him off posaconazole. All I can think of is that he was moved on to the Ciproflaxcin to hide the fact it was someone else that cocked up but Karen is the best one to ask about this.

88. We were given a detailed flowchart of the medication [redacted] would be getting, the routine, and how often he'd be getting it. I asked about certain medications, when they went through the names of them. We were told posaconazole was part of his chemo programme. We asked what it was for, and they just said it was part of the chemo protocol. We were told it was to protect him when he was going through treatment. When you go in to hospital, you go into a wee world of your own, you take whatever the Doctor says as being the word of God because that's their job, that's what they know.

89. They went through the protocol, about certain medications, the timeline was getting them, how he would get a look at artificial boosters, once he started hitting certain medications, chemo for example. Chemotherapy would take his neutrophils to zero so he would have no immune system and would need boosters to bring his neutrophil level back up again. I didn't really know

what his neutrophil level was, but it was clarified that it would be for his immune system because it would be obliterated from the chemotherapy. [redacted] would have a very high chance of catching bugs and other diseases, from other people. The boosters were given to [redacted] by injection and I was trained how to give him those. His legs would be black and blue because of them. I only done it for a short period of time as the emotional side was too hard. I had [redacted] screaming, "Daddy, don't hurt me". That was too hard. I had to say to the nurses that I can't do this anymore. It was difficult as his legs would be black and blue.

90. When we found out what the posaconazole was for, we went back and asked some of the nurses why we were giving him this. That sort of fell on deaf ears, we never really got a response to that. Again, when it was changed at that point to ciprofloxacin, we weren't told why. At that point, we were doing our own research into these types of drugs, and finding out what they were used for, and when we got that information we asked those questions to Dr Sastry and the medical nurses round about that time. Again, it wasn't confirmed or denied, why he was getting it.

Loss of amenity

91. I think parents would still be in the same situation they were in two years ago if we didn't fight for facilities. We fought the Health Board for a parents' seating area within ward 6A, which wasn't available while [redacted] was getting treatment done and we had nowhere for [redacted] to play or for us to cook food in meaning we would have to leave [redacted] on his own in his room. I think that was one of the questions that was raised with them was why we had not had a catering area. I think we mentioned it to Anas Sarwar, MSP, as well. We also voiced our opinion to Angela, who was the staff nurse, why there was no chill out area. After January 2020, the hydrotherapy bath in 6A was removed, and they repurposed that room for a parents' catering area. We welcomed this. It was a sort of lounge area with a microwave, a tea and coffee machine, a chill out area where parents could go to, while they were on the ward, and

they could get away from the children, and go and have an adult conversation with another parent. I don't think the hospital would have bothered doing that if we hadn't fought for that side of it. We thought that the facilities on the adult side were poor, there was nothing really there. They built that facility after [redacted]'s treatment had finished. With Covid, we lost it again, because the parents couldn't use it, and it became a sort of staff canteen area. But while it was getting used, it was there for the parents, which they never had in the past.

92. If I never had any dinner with me, or the two hot meal options I was given at dinnertime was something I didn't like, I had to ask a nurse to stay with [redacted], so I could go down to the Marks and Spencer's on the ground floor and buy something to eat from there. I then had to take it round to the only place where there were two microwaves, in the staff seating area, on the ground floor. I would need to heat my food up in a microwave that was used by most people. The place wasn't the cleanest, there was food splattered all over the place, all the time. You're then having to take piping hot food back into a lift, to go up six floors, into a ward that's got immune deficient patients in it, with hot food. You're carrying a tray of hot food, and going back into a room. You could possibly eat it down the stairs, but you're still having to go down, you're still staying away. If you've got a kid like [redacted] was, who hated when I had to leave the room, he would have tantrums. He would break down because he didn't like it. If I was there, he knew I wasn't going to let anything bad happen to him, and that was it. I could never leave the room, because he would be thinking something bad was going to happen to him.

93. So I was with [redacted] all the time, and then the odd times that I could get away, he wouldn't mind if I went to the shop because he'd know he'd get a chocolate bar, or a magazine, or something like that. Nine times out of ten, he didn't want me to leave the room, I either had to get someone to come and sit with him, or wait until I could.

EMOTIONAL EFFECTS

Overall emotional impact on [redacted].

94. I can't tell you the emotional impact on [redacted]. His body language though, for example, up until probably November 2020, any time we'd attend a clinic and get finger pricks done for blood samples, [redacted] would always fight you on it. It would take maybe four or five of us to hold him down, to get a finger, so they could get a blood sample. I don't know if it's just maturity wise, but it was like a switch went off after November 2020 and then there was no argument. If [redacted] needed to get his finger pricked, then it was okay. You would take a finger, and he'd say to put it in that one there. It's the maturity side of it, he's just grown up a bit. Emotionally, he's very shy now, if he goes into a situation where he doesn't know anybody, he'll cling onto your leg, and hide away.

95. He's very, very quiet until he's sure of you, whereas beforehand it might have been 15 minutes, because he didn't understand the situation. Now it's maybe 45 minutes to an hour before he'll start to drop that barrier, drop that façade. It's a sort of wall he puts up when he goes into the hospital, now. He doesn't talk to anybody; he doesn't give them eye contact. If they ask him to do something, he won't do it. It's only now, as he's not there on a daily basis, that he's slowly coming round, he's getting more back to the way he was before.

COMMUNICATION: GENERAL

96. There was an auxiliary, Andy who was really good and he was your point of contact. He would handle any questions and anything that parents felt disgruntled about. He had been telling his bosses about problems, and nothing was getting done about it. He was one of the first ones to suggest going to the papers, and making the story public, so that they would have to respond to it, because they weren't listening to him. They were there, trying to pass that information on, and he told us that the management didn't do anything and we needed to make the public aware of this sort of thing. At that

time, I thought we would do that, sort of like a whistle-blower, to a certain extent.

97. A lot of staff, including nurses started leaving, they told us they were getting told to lie by the Board, and from their managers. They told me they were getting told to lie to ourselves about treatment, and protocols, and a lot of them just couldn't handle it. They never got into the job to lie, and a lot of the people left. I don't have their names, I know them to see them, and there was a couple of them who went out their way to do anything for you, or for [redacted] because they were seeing him on a daily basis.

98. I think the staff are more forthcoming now with us, because I think they know that we will question everything, we'll stand up and defend ourselves. When we first began this journey, we were very naive, we believed the Doctor knew best, and we wouldn't question anything that was said, or done, or anything like that. We now question the staff, question the doctor, question when they were doing something every time it was going to have an impact on [redacted]. We'll research it, and find out if they're giving him medication, and why they are giving him it. We'll question everything, we'll query it all and if we are not happy, we'll voice that we're not happy, whereas before we probably would have said we'll see how it is. We don't stand for that anymore, we can't, we need to question, we need to fight it.

99. I think communication is better now than it was at the beginning, and how it was last June when [redacted] relapsed. It's a lot better than the previous time when he was in getting his chemo. If we have a query, we can phone up, and they've got numbers for day-care, and the Ward 6A. We can phone up at any time. If we ever have to go into A&E, we just phone up Ward 6A, and they'll phone down. That communication is still there, and any time he has to attend anything else, there will be communication, they'll be forthcoming with information, and happy to help now, more so than what it was in the past.

100. I think the communication between parents is far better than it is between the parents and staff. There’s a lot of questions and knowledge between the parents, that is shared and also given to new parents that are coming into this. I think it's a resource that should be given to parents, when they come in, without having members of staff on, i.e. in Facebook groups. We've found in the past with certain pages that are opened up on Facebook, in regard of talking about things, members of staff are signing onto it, so that they could report back, and report on what we’re saying. I know there is a closed group, but I think they were known by the hospital, and they could be used by the hospital. But they could be used by parents that were going into that, and saying, by the way, the parents have this group, that’s it there, it's a closed group, and you just have to give a wee bit of information so that you can get into it. I think that you'd get a lot more information, a lot more weight, a lot more people behind you to back you up in aspects that you wouldn’t have any knowledge about.

101. I’ve not directly dealt with Professor White. Again, Karen would speak to him more. I was there at meetings, but as a co-parent sort of thing, with other parents that were there. Karen and I had spoken about questions to put to them but she was the main one to voice those questions.

102. I was at two meetings. I think one was with Anas Sarwar, MSP, we had a meeting with him. We had another meeting with Jeane Freeman. I can't remember where it was, just that it was in the teaching part of the hospital. The Facebook members were there as well. I was there more for support for Karen, she does the logistics side of that, and voicing any questions or opinions.

103. The press coverage has had an impact in a positive way. If it wasn’t for the press a lot of things that happened on the wards, wouldn’t have happened. If we hadn’t voiced our opinion, or if [redacted]’s story wasn’t in the public domain, I think a lot of issues that we raised wouldn’t have been sorted out, like the

fridge situation, and the different foods. I don't think any of that would have been resolved.

COMPLAINTS

104. We didn’t make any formal or written complaints. There was one auxiliary who would handle a lot of questions, anything that parents felt disgruntled about, he would be the point of contact. He would be the one that was passing it onto his supervisors, and he said, it was just like it fell on deaf ears. There was no interest in them trying to accommodate parents.

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

105. I can't think of anything I’ve had to do with the Oversight Board or the independent Case Note Review. Again, Karen would probably know about that side of it. It's mainly Karen that would speak to them on a daily basis, so any other person, I don't really speak to. I’m not on the main Facebook groups, or if I'm in the Facebook groups, I don't have any direct contact with those members, it'll be Karen that’ll deal with them.

106. I don't really bother with the hospital Facebook group. I'll catch up with it when I've got time to go on it. Karen deals with that side, she's got the time to sit and talk to people.

CONCLUDING COMMENTS

107. I think the hospital is probably still about the same in the grand scheme of things. With Covid, I think they’ve changed, there's more focus on cleanliness, and PPE. We’re only in there every fortnight, now, unless [redacted]'s got a clinic to go to, but I can't comment on the wards. We don’t go into the wards, and we don't stay in 6A anymore, we’re only in to pick up medical supplies and medication for him, and he goes in and gets a thumb prick done. I can't really

comment on how the running of the is hospital now, because I'm not staying there long term.

108. I don’t think the Health Board have really changed. I believe that when this all came out about the water, they should have sacked them and I still stand on that side, that they should have sacked them. A fresher set of eyes should have come into it. I don't think they should have been able to maintain their job after having a scandal with water borne diseases, and resulting in the deaths of several children. According to any independent results that have come back, they’ve said it wasn’t the water that caused it. Anything that Anas Sarwar has had from any whistle-blowers, reports, or any documentation that we've received, it shows that it was water. I just think they're protecting their jobs; they're sitting on a board to protect the £195,000 of a salary they're getting each year.

109. I have knowledge of people, and knowledge from my family, about the medical side, and medical issues, and medication, things like that. There was talk about these water borne diseases. These have been present in the previous hospital at Yorkhill, and it's as if it's been carried across to the newer hospital. It would be from working practice, more than the site or location of the hospital. It's the way certain processes are done, that these water borne diseases are still present. They were present in the old Yorkhill Hospital, 40 years ago, and they're still present in this day and age. I know it's just down to poor procedural practice, more than anything else, or something else.

110. I understand America is mostly private practice, and we have an NHS system, which is quite different, but comparing the two medical systems, the level of care is night and day. In America, you get what you pay for. I think that’s basically what it comes down to. Obviously, America is private care, but the cleanliness level, or the maintenance from the staff is first-class in America, even when you had a basic area. I just think if they could adopt some of those ways of practice here, we would have a much better NHS system.

111. If you're on the worst journey of your life, and you want a wee bit of emotional support there, to help you along that way, I think that would be great. We didn’t have that crutch, it was a really hard journey for us especially when [redacted] relapsed and we had to fight tooth and nail for treatment so he could still be here. I think it's a hard journey for a lot of people going into that. If it was in the Schiehallion, in the children’s hospital, that would have been a bit better, but because you'd been forced into 6A there were a lot of different other factors that were in place.

112. When we came back from America, we had the money sitting to pay for the extra flights, I think it was £2,500. We had a contact in the NHS but I can't remember the name, Karen would know. We tried maybe two to three times a week, phoning this person up, leaving messages, leaving text messages, leaving emails. It was as if it fell on deaf ears, nobody was chasing it up, nobody was sending the invoice out to us so we could pay it.

113. It got to a point almost three months after getting back from America, we still hadn’t paid it. We were still getting correspondence from the person in question, who it was supposed to be getting paid to, up until the beginning of September, when everything started coming out about the ward issues. And then there was no correspondence at all, we couldn’t contact anybody, nobody was phoning us. You would think if you're due £2,500 to somebody, they would want you to pay it. We never paid it, we never got an invoice for it, we tried paying it, and nobody gave us a bill for it. As I said, we were contacting them two or three, three or four times a week. We were saying, send us an invoice, we want to pay this, we've got the money, we want to get it out the bank. We were sitting there telling them, I want to give you money, I want to give you some money. So the bill was never paid.

114. Nobody has ever contacted us in regard to the bill. It's as if they’ve gone and said something like, I don't know if we should do this, it's as if they’ve said, we won't bill them for that, and it'll be a wee bit of hush money, sort of thing, so

they won't say anything bad against us, or something like that. It's not as if we didn’t try and pay it, we tried.

115. 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.

APPENDIX 1 – AS/01 - TIMELINE

- 20th February 2019 – [redacted] shows signs of being unwell with vomiting and did not seem himself. He attended his GP who advised that [redacted] had a viral illness. His symptoms did not improve.

- Friday 22nd February 2019 - Andrew took [redacted] to QEUH for further checks. He was monitored in accident and emergency and the staff concluded that he had a viral illness. He was sent home with calpol.

- 24th February 2019 - [redacted] attends A & E at QEUH. There were no beds available so he waited in the plaster room. A CT scan is ordered after Karen demands one (staff wanted to discharge [redacted]). Karen and Andrew find out on this day that [redacted] has a “mass” on his brain and that there was a risk it was going to haemorrhage. He is sent for an MRI scan and he then went for an 8-hour brain operation. After this operation he is transferred to ICU for 3 days approx.

- 28th February 2019: [redacted] is moved to ward 2C. He remains there for 10 days

- 6th March 2019 - [redacted] is introduced to Dr Sastry and discharged home.
- Within the same week of the 6th March– [redacted] returned to hospital and had a Hickman line fitted. He was admitted to ward 6A, room number unknown. It was a room at the end of the ward. [redacted] begins his treatment plan around this time (chemotherapy and radiotherapy). During this round of treatment [redacted] was extremely unwell with regular temperature spikes. He was moved into an isolation room and at one point he was told he had an infection. [redacted] was put on Propiconazole at the beginning of his treatment.

- 22nd April 2019 – [redacted] and the family travel to Florida so he can undergo proton therapy for 8 weeks. This was a particularly difficult journey due to the hospital not communicating with the 3 airports about [redacted]’s situation and the route being organised by the NHS without consideration for the family’s situation. While he was in Florida it came to light that he had been on propiconazole. The doctors in Florida queried why this was and contacted QEUH. They were told that was receiving this because the water at the hospital was dirty. Up until then Karen had been told that this medication was part of his chemotherapy (or had that impression).

- 21st June 2019 - The family returned to the UK. The moment [redacted] returned to the UK to QEUH he was put back on Propiconazole. Shortly after returning he also had to undergo strong chemotherapy treatment because he was unable to receive this in America because of the Proton therapy. This meant he went through a period where he was an inpatient for 5 days or so and then a Daycare patient. He was continually in and out the hospital until December.
- December 2019 – [redacted] finishes treatment. His central line is removed. Once the line is removed he is able to stop the antibiotics.

- December 2020 – [redacted] develops meningitis.

- March 2020 – [redacted] has a scan and everything is shown to be clear.

- May 2020 – [redacted]'s behaviour changes, he becomes aggressive. At the end of May 2020 he attends for a scan (which was delayed due to covid)

- 1st June 2020 – The family are told that [redacted] has relapsed. At a meeting on this day with Dr Sastry and Dr Roddy, it is explained that there is an adjacent brain tumour and 3 more spots beside it. Palliative care is suggested instead of treatment by Dr Sastry. Dr Roddy says he could operate despite this palliative care suggestion. Karen and Andrew research treatment options. They find treatment and Dr Sastry denies that he has heard of this treatment, then tells them that this is not available on the NHS.

- 7th June 2020 (approx.) - Karen and Andrew speak with Dr Roddy. They discuss a possible trial treatment. Dr Roddy tells them that before they had met on the 1st June a board meeting had been held with Dr Roddy and Dr Sastry. At the meeting Dr Roddy had suggested operating, which was not backed up by the board. The decision was because of cost.

- Mid-June 2020 - After appealing the decision this was overturned and [redacted] was able to get surgery and receive a trial medication. Had the family not fought for to receive treatment, (due to the NHS saying it was too expensive) [redacted] would have likely not survived.

- [redacted] has done well since this point. He has recently had a scan and there was a fear that he had relapsed. It is now confirmed that he has not relapsed. [redacted] is still receiving chemotherapy and has a feeding tube.