



SCOTTISH HOSPITALS INQUIRY

**Hearings Commencing
20 September 2021**

Day 9
Friday 1 October
Afternoon Session

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(NB: Audio stream inaudible for opening two minutes of the hearing)

(No recording for approx. two minutes)

MS ARNOTT: -- Primary [redacted], is that right?

A That's correct, yes.

Q And it was in Primary [redacted], I think, when he was diagnosed.

A Yes.

Q Thank you.

We'll get started on your evidence, now, Ms Young. What I'd like to do is walk through a timeline of your son's treatment, and as we go, we'll pause to talk about certain aspects of the experience. And we'll begin by looking at events around the time of your son's diagnosis. In April 2018, I understand that your son had been having some pains and particularly toothache, and you had those checked out, is that right?

A Yes. He had an abscess, so he had to have his tooth removed, which we thought was the cause of this pain that he'd been having, but unfortunately, he continued to display signs that he wasn't well. He had a temperature, and I took him to the GP and they had said that it looked like he had an ear infection. So, they prescribed some antibiotics for him, but he just continued to deteriorate over the next couple of days, to the point where I took him

back to the GP. Unfortunately, my local GP -- [redacted] was crying and wouldn't really let them go anywhere near him. And, "Well, there's obviously nothing wrong with him. Just take him home and monitor him." But it was that night that I took him to out of hours to get him checked over.

Q And what happened after you took him to the out of hours? I think that was in [redacted], was it?

A In [redacted], yes. When we took into the out of hours, I told the doctors the exact same as what I told his GP, and they gave him a thorough examination and said, "There's something going on. We would like him to be checked over further," and asked me to take him across to the children's hospital, which is what we did. And we spent a number of hours in A&E waiting to be seen, which eventually we did get seen and he had some blood tests taken. And we were told that he had a raised level of LDH in his blood.

Q So, I understand, I think you waited in Ward 2C, is that right, while you were awaiting the blood results and then after that, your son was moved over to Ward 2A on the 17th of April 2018.

A Yes. When he was first in A&E, he was then taken round to

the Clinical Decisions Unit and then, from the Clinical Decisions Unit, he was taken up to 2C while he had further tests and examinations done. And then across to 2A.

Q Okay, thank you, Ms Young. And then, shortly after that, I think it was on the 18th of April 2018, your son was diagnosed with Stage 4 Burkitt's Lymphoma, is that right?

A Yes.

Q Ms Young, could I ask you how you felt when you received that diagnosis?

A Terrified. Shocked. I thought, "Was this the end for [REDACTED]?" At that point, we didn't really know what Burkitt Lymphoma was, what stage 4 meant for him, what lay ahead. It was a hard time.

Q Okay. Thank you, Ms Young. And I think after that your son was treated in the hospital between April 2018 and February 2019. So, it was a total of about 10 months, is that right?

A Yes. He was inpatient for around six months, and then in and out after that.

Q And were you with your son during his treatment at the hospital?

A I was, yes.

Q And I think you say in

your statement that your mum also helped out, is that right?

A That's correct, yes.

Q I think you said your mum had a room at the CLIC Sargent facility.

A Yes.

Q So, she was on hand to help you out.

A Yes. I didn't want to leave [REDACTED] at all. So, my mum would go to the shop for us, bring any food or supplies that we needed and do all our washing and everything for us. So, it was very handy that she had the room at the CLIC Sargent house that was off the hospital grounds.

Q Okay. Thank you. You indicate your son had a Hickman line fitted a couple of days later, I think that was on the 20th of April 2018, is that right?

A Yes.

Q And am I right in thinking that the procedure to fit a Hickman line involves surgery under a general anaesthetic? That's right, yes.

Q That must have been a lot for your son to deal with in the space of just a few days. So, I was going to ask you how your son felt when he was first admitted to the hospital.

A He was absolutely terrified. From the second that he was admitted to hospital, he'd been poked and prodded, blood tests, CT scans, X-rays, ultrasounds, all sorts of different tests just to find out what was wrong with him. And when he was first admitted on to Ward 2A, he was that scared of everyone coming into his room, I had to put a sign on his door to say, "Please tell me who you are, why you're in my room and what you're going to do to me." Because it doesn't matter if it was a cleaner, a dinner lady, nurse, doctor, it didn't matter, he was just terrified.

Q And putting up the sign help with that, do you think?

A It did. Not everyone took notice of the sign. Unfortunately, some people would still come in and not explain to him what they were doing, but eventually [REDACTED] began to recognise that the nurses were in the blue scrubs, the doctors didn't really have a uniform, the dinner ladies were in a different colour, the cleaners were in a different colour. So, he very quickly realised who they were and what they were doing.

Q Okay. And I think, after the initial admission, your son then went through, I think, a total of six rounds of chemotherapy, is that right?

A That's right.

Q And how did he cope with the chemotherapy itself?

A He was very sick to start with. He slept a lot, he didn't eat a lot, he was bedbound for quite a long time, which has affected his mobility. I mean, overall, for a six-year-old, he coped as well as you can imagine. He still kept smiling. He just wanted to be a happy little boy like he was.

Q And I think you say in your statement that he was so ill with it that he also had to have a feeding tube, is that right?

A That's correct, yes.

Q Before we move on, Ms Young, there's one other matter I want to ask you about, just around this initial period, you say in your statement that you were told it wouldn't just be [REDACTED]'s treatment that could cause them to be very ill, it could be an infection that did that. And was that something you were told near to the beginning of [REDACTED]'s treatment?

A Yes, it was pretty much at the start. Before he even started chemotherapy, when his consultant was telling me about his diagnosis and what was going to happen, she said that infection was something that we had to be very aware of and that it would be likely that that would beat (?) |

before the cancer would.

Q So, would it be fair to say, Ms Young, that you knew that infections were a serious risk to [REDACTED] from a very early stage after his diagnosis?

A Yes.

Q Thank you. Ms Young, what I'd like to do now is move on to look at what happened in May and June 2018, and for those following the statement, we're now around about paragraph 20. So, starting with May 2018, you say in your statement that on the 15th of May, your son developed Vancomycin-resistant Enterococcus – and apologies if I've not pronounced that correctly, but I think it's also known as VRE, is that right?

A That's correct, yes.

Q And when your son had VRE, you said he was put in source isolation.

A That's correct.

Q Could you explain what you mean by "source isolation"?

A So, source isolation, the nurses would come and put a yellow sign on your door, basically, just saying that no one could enter the room without speaking to nursing staff beforehand. It also meant that [REDACTED] wasn't allowed to leave the room and,

because I had been staying with [REDACTED], I wasn't allowed to leave the room either. When my mum would come over in the morning from the CLIC Sargent house, once she entered the room, she was then technically classed as being dirty. So, she couldn't then leave the room and go, for example, into the parents' kitchen or into the playroom or anything like that. And so, we were stuck in those four walls.

Q Ms Young, I think you mentioned one particular incident where [REDACTED] wanted a glass of milk, but you weren't able to get that for him because you were in source. Do you want to tell us about that?

A So, [REDACTED] stopped eating and drinking quite a lot during his treatment because he developed mucositis, which broke down all his mouth. So, whenever [REDACTED] decided that he wanted something to eat or drink, it was really quite important that he got it there and then. But because [REDACTED] was in source, I wasn't able to then go to the kitchen and pour him a glass of milk. So, we had to ask the nurses to get it, and I think it was about an hour to two hours later they eventually came with this glass of milk, and then the notion had gone for [REDACTED]. He didn't

want it anymore. And so, that opportunity for him to have some nutrition was taken away from him.

Q Okay. Thank you, Ms Young. And just staying with this theme of source, I think you describe in your statement, there was one incident when [REDACTED] was in source where there was an issue with stool samples going missing over a two-week period. I wonder if, in the first instance you could tell us what was significant about stool samples while [REDACTED] was in source?

A When [REDACTED] was in source with VRE. Essentially, he would have really quite bad bouts of diarrhoea and in order for [REDACTED] to be able to get out of source, he either had to have-- you had to have negative stool samples that came back and said that he didn't have VRE anymore, or he had to be non-symptomatic, so his stools not being soft or loose anymore. So, the fact that these stool samples had gone missing meant that we weren't getting the results. We didn't know if he still had the infection or not, and whether he needed to be in source.

Q And you say this happened over a two-week period, period?

A Two-week period, yes.

Q And did you receive any explanation why the samples had gone missing?

A No. When I asked the nurses, 'cause I would ask them on a daily basis, "Have you had any results back yet?", they would just say, "No, there's nothing back. There's nothing back." And there was no explanation as to where they'd gone or what had happened to them.

Q Okay. Thank you, Ms Young.

Ms Young, I'd like to move on now to events in June 2018. And from your statement, I think we can see that a number of things happened during this time. What I'd like to do is walk through, first of all, an overview of the timeline in June, and then we'll double back and explore some of these events in a bit more detail. On 1st of June, I think you were told that your son had a fungal infection, but am I right in thinking you weren't told the name of it at that time?

A That's right, yes.

Q We'll come back to that in a moment, Ms Young. But shortly after that, I think you were moved to a room with double doors, is that right?

A Yes.

Q And were you told about the reason for that room move?

A We had a number of room moves while we were on the ward. This was just another one of those occasions. The reason behind the room moves, we were told that they had to clean the rooms. And this happened on a number of occasions.

Q And about the same time, so this would be, I think, on the 5th of June 2018, you were told that your son was going to be put on a drug called ciprofloxacin – and again, I apologise if I've not pronounced that correctly – but you were told he was going to be put on that drug as a precautionary measure. Who told you that?

A It was a doctor.

Q And pausing there, Ms Young, I think within the space of five days, so from the 1st to the 5th of June, you'd been told that your son had a fungal infection. He was moved out of his room so that it could be cleaned, and you were then told that your son was being put on another medication as a precautionary measure. Did you think there was any link between those three events?

A At the time, I didn't really connect the dots. I was just so focused on what [REDACTED] was going through at that moment in time, but looking back on it now, yes, it does

look like there could have been a link between the three things happening.

Q Okay. And moving on, Ms Young, on 6th June 2018, I think you say in your statement that you were moved room again, and again, the reason was given that the room had to be cleaned. Would you describe what you saw happening to this particular room?

A That particular time that we moved, once we had vacated the room, we weren't allowed to take any of our belongings with us, apart from basic toiletries that we needed. And once we vacated the room, they put a clear sheeting over the door. And there was a machine outside that had a vent into the room, and it was like a mist that was sprayed into the room. And we were told that it was some sort of cleaning agent that would disinfect everything in the room, which is why we weren't allowed to take our belongings as it all needed to be disinfected.

Q Okay. Thank you, Ms Young. And the next day, so on the 7th of June 2018, I think you say, [REDACTED] was put in source again. And was that with VRE again?

A Yes.

Q And then on 10th June, so again, just another couple of days

later, [REDACTED] developed blisters on his body. And initially, chickenpox was suspected, but you indicate in your statement there was a bit of confusion about whether [REDACTED], in fact, had chickenpox. I think you were told he didn't have it, and then he did. Do you want to tell us a bit about that?

A Yes. So, [REDACTED] just developed blisters on his skin, and he was started on acyclovir intravenously as they suspected he had chickenpox. The doctors took a swab of the spots, so that they could be sent away and tested, and they said that if he did test positive for chickenpox, he would need to be moved off the ward 'cause of the infection risk to other children, and there were some pregnant nurses on the ward as well.

So, I think it was two days later, a doctor came in and said that the swabs came back negative, his medication would be stopped, and they would just keep an eye on the spots that were on him. And then, I think it was another two days after that that his consultant came in to see us, and she apologised to me because the results had been misread. The confusion was that the test that had been done had been done on the

same day, just a different month, so it looked as though the test result had come back negative, when in fact that was for something completely different, and he did, in fact, have chickenpox.

Q And he remained on the ward during that time while he had chickenpox?

A Yes, he did.

Q Now, just to round off the overview of this timeframe, so this is May to June 2018. I think you say during this time, you were told something about the pipes behind the sinks in the rooms. I wonder if you could tell us about that.

A Yes. So, we were told that they were gonna be replacing the pipes behind the sinks because there was children getting water infections on the ward. And it was actually another parent that told my mum that the bug that they'd found was something that stuck to plastic, which was why they were changing the pipes behind the sinks.

Q And do you recall seeing the work being done?

A I can't remember whether we were on the ward at the time or whether we were out the room, but I do remember them coming to do it. I just can't remember if we were in the

room or not at the time.

Q Thank you, Ms Young. What I'd like to do is pause there and reflect on some of the events during this timeframe that you've described to us already. I'd like to start with the healthcare infections that you've mentioned over this period. And for those who want the statement reference, we're now at paragraph 66 and 67. You've said [REDACTED] had VRE, I think at least twice during that period, is that correct?

A Probably more than twice.

Q And what did you understand VRE to be?

A I understood that VRE was a hospital-acquired infection. And I think it was classed as a super bug type infection that he had. I understood that it was passed through touch. Well, I wasn't allowed out his room, so it's been brought into his room by maybe doctors, nurses or cleaners. I don't know who because it's through touch. So, someone's touched something, and this virus has then been transferred through to [REDACTED]'s room.

Q I think you say in your statement, and I think this is at paragraph 66, that you were doing a lot of cleaning of touch points in the

room, is that right?

A That's correct. I was quite paranoid about [REDACTED] picking up any bugs or infections, so I would always-- We had antibacterial wipes in the room, and anywhere that nurses would touch, or doctors, or anyone would touch, I would go around the room three, four, five times a day just cleaning down everything to try and keep it as clean as possible.

Q And what were you told about VRE at the time?

A Just the it was resistant to any antibiotics, so there was nothing we could do to actually treat it, and we just had to ride it out and wait for it to go away.

Q But you were told it was VRE and you were given some information about it?

A A nurse printed off a sheet, just explaining what it was and handed me the sheet to read.

Q And were you concerned about cleanliness in the room at this time?

A Yes. I mean, the rooms got cleaned daily, and when [REDACTED] was in source, they were cleaned twice a day. But I wouldn't put [REDACTED] on the floor to play, put it that way.

Q Yes. And did you have a particular concern about the floors?

A Even after they've been cleaned, if, for example, [REDACTED] split something on the floor and I was to clean it up, and you would wipe round, your cloth would be completely black. It was pretty dirty.

Q Okay. Thank you, Ms Young. I'd like to move on now to think about the fungal infection you mentioned on the 1st of June 2018. Now, in your statement, you mention that the staff were baffled by this infection. Could you explain what you mean by that?

A So, [REDACTED] had raised infection markers and we were told that he had a fungal infection, but they couldn't find where this fungal infection was coming from. They did multiple tests, he had eye tests, he had ultrasound, CT scans and eventually they found that he had a ball the fungus on his liver. That's all I was ever told about it, just that he had a ball of fungus on his liver, and he was put on extra antifungal medication to treat this.

He was already on antifungal medication at that point. He was on a drug called Ambisome, which was given three times a week. And when he was diagnosed with the fungal infection, they increased the dose of Ambisome that he was on, and he was

given it daily for-- I think it was around two to three weeks he was given this.

Q Thank you, Ms Young. Did the increase in dosage of Ambisome have any effect on [REDACTED] ?

A Well, it took almost two weeks for the fungal infection to clear. But the Ambisome, when [REDACTED] had it, he had a reaction to it. So, every time he had to take it, he had to have Piriton, so again, an extra medication that was added in just so he didn't have an allergic reaction to it.

Q And when you say he had a reaction to it, did it make him sick? Or was it a rash? Or what kind of reaction was it?

A It was a rash on his chest and on his cheeks. He went quite flushed, and he had a rash on his chest.

Q Okay. And what effect, if any, did the fungal infection have on [REDACTED]'s chemotherapy treatment?

A His chemo was delayed by, I think, it was 10 days. You had to wait for his infection markers to become below a certain level before they would allow him to start his next chemotherapy.

Q Thank you, Ms Young. And were you told what the fungal infection was at that time?

A No.

Q Do you know what it is now?

A Yes. I requested [REDACTED]'s medical records once he was out of hospital, and after reading his medical records, I've then discovered it's something called aspergillus fumigatus, if that's how you pronounce it.

Q Okay. Thank you, Ms Young. You've mentioned that during this time, again, in the May/June 2018 timeframe that there was some communication about preventative antibiotics. And for those following, we're now at paragraph 75 of the statement. You say, in paragraph 75, that [REDACTED] was put on "prophylactic antibiotics ... as part of his treatment protocol." Is that right?

A Yes.

Q Now, you also mentioned that on the 5th of June, you were told that [REDACTED] was being put on ciprofloxacin, is that right?

A Yes.

Q And just to help me understand, was the ciprofloxacin something additional to the prophylactic antibiotics that [REDACTED] was already on as part of his treatment?

A I believe so, yes.

Q And what was your understanding of why your son was put on ciprofloxacin?

A We were just told that any child that had a central line fitted would be starting this medication as a precautionary measure. That's all I was ever told, and I didn't have any further explanation as to why he needed to be on it.

Q And just to be clear, was it just [REDACTED] that was put on this drug or were other children put on it?

A I believe every child on the ward that had a central line was put on this drug.

Q And was it someone on the ward that told you about the drug?

A No, it was a doctor that told me that he was going to be put on that.

Q And at that time, were you asked if you wanted [REDACTED] to be put on ciprofloxacin?

A No, we were just told that that's what was happening.

Q And what was the effect of that? I'm just going to call it "cipro" now, if that's okay? What was the effect of the cipro on [REDACTED]?

A [REDACTED] was quite violently sick. Well, as I said earlier, [REDACTED] had an NG tube fitted, and when he

was violently sick, on some occasions, this tube would come out, which meant he then had to have it passed again, which was a very traumatic thing for [REDACTED]. He had to be pinned down by myself and my mum, nurse and then the person that was inserting the tube. Very traumatic for him.

Q Okay. And I think you mentioned in your statement you think he might have been prescribed a different drug at that time, is that right?

A Yes. Because he was being so violently sick, they said they had an alternative. I can't remember what the name of the drug was, but it was an alternative to the ciprofloxacin that he was put on.

Q And that was because of the severe effect of the cipro on [REDACTED] ?

A Yes.

Q Okay. So, sticking with May and June 2018, you say in your statement, I think, that it wasn't just these healthcare-related issues that you faced during this time. You've also described other events relating to the hospital environment during this period, and I think particularly in relation to the water. I'm going to come on and ask you some questions about those, and the statement reference for this is beginning at

paragraph 58.

Now, in your statement, you say that "there were filters on the taps and showers". Can you tell us what you observed with those?

A From the moment that we were admitted to the ward, these filters were on the taps. We had asked what they were for, and we were told that it was just standard as part of the hospital building that these filters were on the taps.

Q And were they changed?

A Yes. I'm not sure how often they were changed, but throughout our stay, there was a number of occasions where, I think it was, external contractors would come in and change these on both the showers and the taps.

Q And at some point during this time, were you told that the water from the taps was not for drinking?

A There was a sign on the wall in the room saying that it was not drinking-- It was for hand washing only. But we were never actually told by anybody not to drink water.

Q So, you had to rely on seeing the sign telling you not to do that?

A Yes.

Q I think you also describe seeing workmen pouring chemicals

down the drains, is that right?

A Yes. They came in one day, and it was down the sinks and down the drains in the shower, and we were told not to use the shower for a certain amount of time afterwards.

Q When you say they came in, did they just come into your room?

A A nurse had said that there was gonna be contractors coming in to do this. But yes, they came in whilst we were in there and just poured it down the drains.

Q And were you told why they were coming in to do it?

A Just to clear the drains.

Q You've also mentioned already you were told that the pipes behind the sinks had to be changed. Was that happening at around this same time?

A Yes.

Q Okay. And I think you mentioned that you were told by another parent that that was the link-- Sorry, carry on.

A Sorry. It was my mum that was told by another parent---

Q I see him.

A -- that that was what was happening.

Q Okay. And I think your mum was told that there is some link between that work being carried out

and possible infections in the water, is that right?

A Yes.

Q Okay. Were there any other issues you observed in relation to the water or showers on Ward 2A?

A With the showers, very quickly after we were on the ward, I noticed that every time I had a shower, it would pretty much flood the whole area. So, I would have to get multiple towels and place it all round the room and the shower to stop it seeping out into the bedroom. And also, the seals that were around the shower, they would quite often be lifted away from the wall or cracked. Not very pleasant.

Q I think in this time you also say you observed some rooms being sealed off and cleaned, is that right?

A Yes.

Q Did these things that you observed was you any concern at that time?

A We just wondered what was going on and why was it going on. Like I said earlier, we had multiple room moves during our stay in the hospital, and when you're living in the hospital-- I mean, [REDACTED] was an inpatient for six months, so he managed to gather up lots of toys and things like that, and we were being

moved almost on a daily basis to a different room so that the room we were in could be cleaned. It was just such an upheaval for us and for [REDACTED] and we didn't know whether we were coming or going.

Q So you've described there was obviously an inconvenience there. But I think in your statement at paragraph 59, you also suggest that these issues had caused you some concern about "patient safety", is that right?

A Yes. Obviously, infection was a huge, huge thing for children that were immunocompromised and, quite often, throughout [REDACTED]'s treatment, he would be immunocompromised, and we just didn't know whether the rooms were safe to be there-- for him to be in the rooms or not.

Q Okay. Thank you, Ms Young. Thinking now about the communication about these issues, what, if anything, were you told about the issues with the water?

A Very little. We would ask-- We would see things in the news and we would ask the nurses, and they just would say, "Oh, we don't know. There's nothing wrong." And when we were being moved rooms, we would occasionally be handed a letter.

Unfortunately, I don't have any of these anymore, but sometimes we would be given a sheet of paper just saying, "This is what's-- You're being moved rooms for cleaning, etcetera." But, yes, there was very little communication about anything to do with the water.

Q So, to be clear, you weren't told why anything that you saw happening was happening at that time?

A No.

Q At paragraph 63 of your statement, you describe asking the nurses about why filters were being placed on the tap, and you say the response that you received was that it was "part of hospital protocol", is that right?

A Yes, part of the hospital building, the way it was built.

Q Part of the hospital building and the way it was built?

A Yes.

Q And were you told anything about why the pipes behind the sinks were being changed? I think you've already given us an indication of that.

A Only what we heard from another parent, not directly from any staff.

Q But I think the suggestion

was that there may be a link to children getting infections on the ward.

A Yes.

Q So, Ms Young, if I could just pause to reflect on the chapter of evidence you've just given us: in a matter of weeks, on top of his cancer diagnosis, your son had VRE at least twice, he had a fungal infection, he had been in source frequently, and you've been told that he needs to take preventative antibiotics because of his central line and, on top of that, you've seen a number of indications there's an issue with the water on the ward, and you've also seen rooms being closed off for deep cleaning. How did all of these events make you feel?

A Scared. Worried. We were in an already stressful situation being at the hospital dealing with cancer, and then we were being given all these extra things to deal with. Yes, it was very stressful and a very scary time.

Q And what would you say was the effect on your son during this time?

A He didn't really know-- We tried to keep a lot of what was going on away from [REDACTED]. We didn't want him to have any extra stress or any extra worries. We would just try and keep him occupied. He

loved doing arts and crafts and things, so we would just do lots of different things with him throughout the day to keep his mind occupied and not discuss in front of [REDACTED] anything that was happening, or we would just try and make it fun for him.

Q Okay, thank you. Ms Young, in your statement you describe some further issues around this time which affected your experience. I'd like to move on now to look at those, and this is at the section beginning at 78 of your statement. You indicate that you didn't like the fact you couldn't open the windows. Could you tell us why?

A It was very, very hot on the ward. We were told that we couldn't even have a fan because of infection risks. There was no way to control the temperature, although there was a temperature gauge on the wall. Didn't matter if you pressed up or down, it wouldn't make the room any cooler or any hotter. It was just unbearable to sit in the rooms at times.

Q And did you think that there was any link between the heat in the rooms and your son's temperature spikes?

A Well, [REDACTED] would get temperatures quite frequently, and when he did get a

temperature, there was no way to keep him cool because the room was so hot. We didn't know if that was causing him to have temperatures or whether it was an infection.

Q At paragraph 83 of your statement, you describe that the staff had quite an unusual way of trying to keep the ward cool. Could you tell us about that?

A They would turn the lights off. They would say that with the lights being off on the ward, it would help keep the ward cool. Quite frequently throughout the day, the lights would be off on the whole ward.

Q Okay, and that's the reason the staff gave you, was to try and keep it cool?

A Yes.

Q I think you say you also had concerns about the cleaning of the rooms. You've described some of that already, but I wonder if you could explain what you observed with the rooms being sealed off.

A So they were all sealed with, like, a plastic sheeting over the door, and there was some kind of machine that would sit outside, and it had a hose-type thing that would go through the sheeting and a mist would be sprayed into the room, and we were told that it was to disinfect everything

that was in the room.

Q And I think you've already described the consequence of these rooms being sealed off, or at least you perceived that was why you were moving rooms so often, is that right?

A Yes.

Q You also mention that you felt the bedding was not changed very quickly if it became soiled. Could you tell us about that?

A So when [REDACTED] was first admitted to the ward, parents were allowed to go and collect bedding and change as and when required. But, as time went on, it appeared-- well, we were told that we were no longer allowed to go and collect the bedding; we had to have a nurse bring it to us.

So, as I said before, [REDACTED] was quite violently sick quite a lot of the time that he was in hospital and he was very sweaty throughout the night, so we would have to change his bedding multiple times a day, and obviously we were told we weren't allowed to then go and collect the bedding. We had to ask a nurse. But they were just so busy dealing with other patients or giving out medication, chemotherapy, that sometimes it could take hours before you would be given

fresh sheets.

Q And if it was taking hours to get fresh sheets, does that mean that [REDACTED] was left sitting on a mattress on his bed?

A (No audible reply).

Q You also say in your statement that stool and urine samples were left sitting for a long time in the bathroom. Could you tell us about that?

A Yes. So, again, when we were first admitted to the ward, we were-- they would measure the input and output of fluids for [REDACTED], and we were allowed to take the urine samples or stool samples along to the sluice room, and we would just write a name on it and then the nurses or auxiliary staff would go in and deal with it and put it in his notes. But, as time went on, and all the room changes were happening, infection seemed to be getting higher on the ward, we were then told that we were to leave these samples in the bathroom and nurses would then come and collect it and take it away. But we had multiple samples left in the room for hours and hours and hours, and we would keep asking, "Can you come and take them away? You know, it's hot in the room, they're smelly," and it would take hours for them to come and

get them sometimes.

Q Okay. Ms Young, would you mind reading out paragraph 88 of your statement for us?

A

"Sometimes the samples were left for hours and hours and you could have 6 or 7 sample pots sitting in the bathroom waiting to be collected. As you can imagine, sitting in a room that's warm, the smell was bad. I didn't think it was hygienic them being left to sit that long but again, it was down to the nurses' workload. They just had so many extra things they had to do that parents had been allowed to do before and now weren't allowed to do. It had all been put on to the nurses. Nurses had a lot more tasks to take on due to new protocols for infections on the ward."

Q Thank you, Ms Young. Could you explain what you mean by the "new protocols for infections"?

A So, again, when everything started happening, we were not allowed to go to the sluice room to take the urine samples, we weren't allowed to go and get bedding. We had to rely on nurses or auxiliary staff. When [REDACTED] was in source, I

wasn't able to go out and use the kitchen, so we then had to ask for the nursing staff to go and get anything that we needed from the kitchen, whether that be juice or anything for [REDACTED] or (inaudible) my dinner to be heated up in the microwave kind of thing. So they just had so much extra work that they were being asked to do.

Q And was your perception that the nurses were really now overloaded with these extra tasks that they had?

A Yes.

Q Before we move on in the timeline, Ms Young, you also say you had a concern about the smell of sewage around about the hospital. Could you tell us about that?

A Yes, so when you were in the car park and you were walking up to the hospital, there was an overpowering smell of sewage, and that could be smelt inside and outside of the hospital.

Q Could you smell that on Ward 2A?

A Yes.

Q Ms Young, if we turn back now to the timeline of [REDACTED]'s treatment. I'm going to pick it up again in July 2018, and the statement reference for this is 31. Now, you say, I think, that your son had a third round

of chemo which started on the 17th of June 2018, is that right?

A Yes.

Q And I think you say he was unable to complete it because of his blood counts being too low. But he eventually restarted it, and it was around about this time there was an issue with his anti-sickness medication. Could you tell us what happened with that?

A Yes, so [REDACTED]-- his blood counts hadn't recovered enough for him to be able to start the last part of cycle three of his chemotherapy, so that day he was given permission to attend a family wedding. He was given a day pass.

When we got back from the wedding, he was then due to have his medication, so the nurses came in and they administered all his medication to him, one of which was an anti-sickness drug. Later on that evening, I was lying in bed with [REDACTED] and a nurse came in, and she-- I think we were watching a film and she administered some more medication to . To be honest, I didn't really question it at the time because we were both tired, we were relaxing after the day that we'd had, and it wasn't until the next morning that we discovered that this nurse had given [REDACTED] a

second dose of his anti-sickness medication, and in fact he'd been given an overdose of it because the nurses that administered it at teatime hadn't signed off that they'd actually given it to him, so then he was given an overdose of anti-sickness medication.

Q And what was the effect on [REDACTED] of that?

A He was then left for a number of hours before he was allowed to have the medication again because he had to wait for it to come out of his system before he was then allowed to have it. And [REDACTED] was violently sick, which-- His NG tube came out, so then he had to have that passed, which was, again, a traumatic thing, having to be pinned down. So this-- Having an overdose lead to all these events happening.

Q Okay. And then, I think, shortly after that, you say that [REDACTED] had to have some teeth removed because of his chemotherapy. Could you explain what happened with that?

A [REDACTED] had some holes in his teeth and, due to the risk of infection to [REDACTED], they decided that he had to have teeth removed. So he was-- Under general anaesthetic, he had five teeth removed.

Q And I think you say that, after that, [REDACTED] was a bit worried about the tooth fairy, is that right?

A Yes.

Q Did she come?

A He was quite worried that she wouldn't know where to go, so we wrote a letter and popped it on his door just to sort of say, "I'm here. My teeth are here," kind of thing. And the nurses, bless them, they wrote a letter back to him to say, "We know where you are and don't worry, we'll-- Just leave your teeth out and we'll make sure that we come and see you." So that was quite nice for [REDACTED].

Q Okay. You go on and describe that, during this period, the nurses were very busy, which you've already told us about. In particular, you describe an incident on the 21st of July 2018, and the reference here is paragraph 36 of your statement. I think you say [REDACTED] had suspected sepsis. Could you tell us what happened here?

A So [REDACTED] was spiking temperatures that were over 40. They never actually said to me that they suspected he had sepsis. It was reading his medical records later on that I discovered that that's what they had been treating him for. They

didn't know whether it was an effect of his treatment. They just kept saying that the chemotherapy that he was on could cause these temperatures, but they never once told me that they suspected it was sepsis. It was in his medical records.

But, yes, he was spiking temperatures of over 40 and he was left for a number of hours without paracetamol because the nurses were busy doing other things.

Q Okay. So your perception was that the nurses weren't able to follow the usual protocol, which would be to administer Calpol or paracetamol straight away, and your perception was that that was because they were too busy?

A He would spike a temperature, eventually be given paracetamol, and then probably, I think it would maybe be around two hours later, his temperature would have crept back up again, so we were waiting for the four-hour mark so he could have further Calpol, and it got to the four-hour mark and nobody came. We were buzzing saying, "██████████ needs Calpol. His temperature's still up. Please, can somebody come?" And I think it was roughly about 45 minutes after the four-hour mark, when he'd had already had a temperature

from two hours previous, that he eventually got given Calpol and we were told, "Sorry, we were administering chemotherapy to another patient. We couldn't come."

Q Okay, and would I be right in thinking that before the nurses became particularly busy, they would usually be pretty good at sticking to these timeframes?

A Yes, because whenever anyone spiked a temperature, the immediate reaction would be there's some kind of infection there, and it was very important to bring his temperature down, take blood samples and start antibiotics.

Q Okay. Thank you, Ms Young. I'd like to move on now to August 2018, and you describe in your statement there was an incident where workmen appeared suddenly outside the building – I think, in fact, outside your room – and started to remove the cladding. Could you describe what happened with that?

A So I believe it was around about the time of the Grenfell fire. They discovered that the cladding that was used on the hospital was the same cladding, so there was scaffolding up all around the outside, there was a blue film put over the windows and they started removing all

the cladding from the building.

Q Were you given any warning that this was going to happen?

A No. The first warning I had was the sound of workmen at I think it was around-- I think I say 7:53 in the morning. The workmen started outside the window and we didn't know anything about it.

Q Okay, and do you have any idea how long this work went on for?

A It was a good few weeks. I can't be certain of exactly how long.

Q And were you able to use the entrance to the children's hospital at that time?

A No. We were told that we weren't allowed to go through that entrance because of all the dust that was created from there. We were asked to use an alternative entrance.

Q And where was the alternative entrance?

A Through the adult side of the hospital.

Q What effect did that have on you and [REDACTED]?

A Well, when they were-- when we were coming through that bit, there were patients standing outside smoking in large groups, and [REDACTED] was in his wheelchair at that point so

he was sort of lower down, and walking through it was just (inaudible).

Q Did it cause you any concerns for [REDACTED]'s safety?

A Well, when you're being told they can't walk through the children's entrance because of dust, but it's okay for them to walk through a cloud of smoke ... not exactly hygienic.

Q Okay. Thank you, Ms Young.

So, to complete the August 2018 timeline, you say your son went into remission, I think, on the 31st of August 2018. We saw that he still had a final round of maintenance chemotherapy to go in September, is that right?

A Yes.

Q And after that, he was discharged to CLIC, I think, to keep him close to the hospital for a while.

A Yes.

Q Now, later on in September, I understand from your statement that [REDACTED] spiked another temperature and ended up being admitted to Ward 2A on the 25th of September 2018, which, I think, as we all now know, was the day before the ward was due to move to the adult hospital, is that right?

A Yes.

Q Yes. If I could just pause

there to think about events surrounding the move to the adult hospital, could you describe how you discovered that the Schiehallion unit was being moved?

A Watching the news.

Q Watching the news, and what date was that on? Sorry, I should have given you a paragraph reference. We're at paragraph 40 now.

A The 18th of September, I think it was.

Q Okay, and I think you say you were in CLIC Sargent House at that point, is that right?

A Yes.

Q So you heard about it on the news on the 18th of September in CLIC Sargent House. Am I right in understanding that you had, in fact, been in the Schiehallion unit the day before that on the 17th of September?

A Yes.

Q Yes, and nothing was said about it when you were in?

A No.

Q And that was even though your son was due back in the Schiehallion unit on the 19th of September for a blood test?

A Yes.

Q Okay. So, when you heard this on the news and you were over at CLIC House on the 18th of

September, what did you do knowing that you were due back in the next day?

A I phoned the ward, just to speak to the nurses to find out what was happening and where we were to go the next day. The nurses didn't know anything about what had happened. They'd only heard what was in the news also, so they just said----

Q So your impression-- Sorry, Ms Young, your impression was the nurses had also heard this on the news?

A Yes.

Q So they weren't able to assist you with any information about what was going to be happening?

A No. They said just to go to Ward 2B, which was day care, just as normal.

Q Okay. I think you go on and say that on the 20th of September, you received some form of letter about the ward move, is that right?

A Yes. When we attended day care, the nurse in charge handed us a letter just to let us know that we would be moving across to Ward 6.

Q Okay. Now, I think you say that ██████████ ended up on Ward 2A having spiked a temperature on the 25th of September, so we now

know that the ward move was due the next day. Would you describe the scene on the ward on the 25th of September?

A It was like organised chaos. There was nursing staff, contractors – I think external contractors that were brought in to help move all the furniture – nurses packing up medication, equipment. It was just absolute chaos. You didn't know who was who. There were just so many strangers on the ward, and we were pretty much told just to stay in our room and wait for our turn to be moved.

Q And you've said you thought there were external contractors coming in. Were the nurses involved in the move as well?

A Yes, they were packing up all the medication and all the equipment, and they would be assisting with patients going across to the adult hospital.

Q Okay. Did you feel it was going smoothly?

A As smoothly as it can be when you're moving a whole ward. I feel like the patients were kind of ignored that day because they were just so busy with everything else. It was just like, "Well, we'll get to you when we get to you," kind of thing.

Q Ms Young, in your statement at paragraph 43, you say something about your perception of whether the nurses could actually go back to their normal nursing duties immediately after the ward. I wonder if the easiest thing to do would actually be to have you to read out paragraph 43, if you could.

A "██████████ was an inpatient on ward 2A on 25 September 2018, having spiked a temperature. This was the day before the move to the QEUH happened on 26 September 2018. It was organised chaos: there were no additional staff to help. Nurses were looking after everyone and everything. They were packing up everything in all the different rooms, all the equipment, medication and furniture. ██████████ had to wear a mask on his face. Once we moved over to 6A, they then had to unpack everything. This impacted how they were able to deliver care as you never really saw the nurses in the rooms at this point. Children are supposed to have their observations taken every 4 hours, but the nurses were just so busy with the

unpacking and moving that the student nurses would get put in to do the observations.”

Q Okay, so your perception was that observations were not happening in the usual way they would that day?

A Yes.

Q Okay. I think you also say something at paragraph 44 about what was happening during temperature spikes. Could you tell us about that?

A So they were supposed to get their observations taken every four hours. Sorry, can I just have a read of the----

Q Of course you can. Yes, sorry, it's paragraph 44. That's my fault. I think you mention towards the end of the paragraph about the usual protocol for blood cultures being sent off.

A So when he was to spike a temperature, he would have blood cultures taken and then antibiotics started. But he was spiking temperatures, sort of, quite consistently throughout, even though he was on antibiotics. So he wasn't getting further blood cultures taken, so they didn't know if there was still a further infection growing, or whether he had to have his antibiotics changed.

Q Okay. So your perception was that staff were so busy, they weren't able to be taking the blood cultures in the usual way that they would during that time?

A Yes.

Q And how did all of that make you feel?

A Worried and, again, scared. You know, we were told right at the beginning that infections were one of the most dangerous things for ■ while he was being treated for the cancer. And every time he spiked a temperature, immediately your mind goes to, “Is there an infection there? Is this something that's going to seriously harm him?” And you just wanted to make sure that they've covered all bases, and they were just so busy that they weren't paying attention.

Q Okay, and do you know how ■ felt during this move?

A Again, we tried to keep everything from ■. He was-- Apart from the obvious moving, he quite oblivious to everything that was going on. He was obviously asking questions why he was moving, and we weren't really able to give him an answer to that, but we would just try to, again, make it fun for him and say

that he was going to get to go on a ride in his bed and things like that.

Q Okay, thank you. I'm going to move on now to talk about your experience in Ward 6A. Just for the statement reference, we're now at paragraph 45. Was there a playroom on Ward 6A?

A No.

Q No. Did you still have the play leaders coming up?

A Yes. The play leaders were there. They would come into the room and ask if [REDACTED] wanted any activities to keep him entertained, but they didn't have the facility to have everything on Ward 6A. So if [REDACTED] said he wanted a certain activity, whether it was painting or drawing, they would then have to go back to their storeroom and collect all of this, which, I believe, was in the children's hospital.

Q Okay, so was that some distance away from Ward 6A?

A Yes.

Q And what was the effect on [REDACTED] of not having a playroom and the play leaders not quite being able to do their jobs properly?

A Well, he was bored. He didn't have anything to keep him entertained. As I said before, [REDACTED]

likes doing a lot of arts and crafts things, so the play leaders would quite often bring in like ceramic things for [REDACTED] to be able to paint, whether it was cups, money boxes, different things like that, and he just didn't have any of that when he was on Ward 6A. He was-- It was just basically him and his iPad.

Q And was there a parents' kitchen on Ward 6A?

A No.

Q And what was the effect of that on you and your mum?

A We were then unable to store any food. My mum would just bring stuff over in the morning from the shop, and we would just have to try and keep it cool in the room.

Q Okay. Now, just moving on a little. In October 2018, I think you say you were staying in the CLIC Sargent facility and going over to 6A to get your son's lines line cleaned and bloods checked? Did you experience any issues with the line around this time?

A Yes, when he was getting his dressing changed, we noticed that he had, like, a crusty part around the entrance of his line. We mentioned this to the nurses, and they used-- it was like an alcohol roller type thing to clean the line, but they also

put-- it was like a little foam pad on the top of his line. They never took any swabs or anything, so we didn't know if there was an infection there, it just worked quite red and crusty around the entrance of his line.

Q Okay, thank you. In your statement at paragraph 48, you describe the experience of travelling up to Ward 6A, I wonder if you could tell us about that?

A We had to come through the adults' entrance which was where everyone was stood outside smoking, so that initially was not a good start. But then we had to use the lift to get up to Ward 6A, and these lifts were the same lifts that all the other patients from the adult side would be using. Patients, visitors, staff. [REDACTED] was in his wheelchair and, when we would go inside the lift, it was just basically how many people can you fit in, so it was really cramped and, you know, he'd have dirty hands in his face. You don't know what these people are in hospital for, where these people have come from, whether they are carrying any infections – are they unwell? It's just quite an awful experience.

Q I think it's obvious from what you've just said, but what was your actual concern about this?

A That [REDACTED] was going to get an infection from somebody?

Q Okay. Now, you indicate in your statement that there is a physical link between the children's hospital and the adult hospital. I think you say there's a corridor. Could you use the children's hospital entrance to get up to Ward 6A?

A You could use it, but we were told not to use it. We were told to use the adult entrance.

Q Okay, and do you know why that was?

A Because of the cladding that was getting removed.

Q Okay, so there was still cladding works going on in the children's hospital, so you were told not to use the children's hospital entrance and to go in through the adult hospital. Okay, and when you got up towards 6A, how did you access day care?

A You had to walk through the whole of Ward 6A before you got to day care which was located at the end of the ward.

Q And did that cause you any concerns?

A Yes, thankfully [REDACTED] wasn't an inpatient on Ward 6A very often, it was mainly daycare that we

attended on 6A, but – walking through – I was concerned for not just [REDACTED] but for the other patients, were we bringing in anything into the ward? Was it safe for other people? Was it safe for [REDACTED] to be walking through the ward? Yes, not nice.

Q And you say, on the 19th of October 2018, [REDACTED] “rang the bell”. Can you tell us what that means?

A And so ringing the bell just marks the end of his treatment. It was such a special day just to see that he’d finished his treatment, he’d finished his chemotherapy, he got through the other side, and it signified the road home.

Q How did you feel at that time?

A Happy, pleased, proud.

Q How did [REDACTED] feel?

A He was nervous, he didn't really know-- He had a lot of people there watching him, and so he was quite nervous doing it, but he was happy. And it meant that, you know, we were near to the end of everything that had happened.

Q Okay, I think you say that, after that, [REDACTED] was discharged to the CLIC Sargent facility again. And, just moving on towards

the end of the timeline of [REDACTED]’s treatment, I think you say that [REDACTED] had a few other admissions towards the end of 2018 and into the start of 2019. I think you say he had his central line removed in November 2018; is that right?

A Yes, yes.

Q And on 10th December 2018, he was admitted and diagnosed with respiratory syncytial virus, RSV; and he was admitted to a different ward in the children's hospital, is that right?

A Yes, I think it was Ward 3, but I'm not sure exactly.

Q And did you understand why he wasn't admitted to Ward 6A?

A We were told there was no space for him.

Q Okay. And then, on 6th of January 2019, I think you say in your statement he was admitted to Ward 2C with shingles and was supposed to be there for about two weeks. But while you were there, on the 18th of January 2019, you saw a story about the pigeon droppings in the press. Do you recall what the story said?

A Just that there had been a pigeon droppings found in the ventilation system and that it posed some risk to the children that were in

the hospital. I had asked a member of staff, "was it safe for [REDACTED] to be there?" He still had some treatment to get for the shingles that he had, and all of a sudden we were then told "[REDACTED] can be discharged today, and you can go home."

Q Ms Young, I wonder if you could read paragraph 95 of your statement for us, please?

A

"I saw on the news about the pigeon droppings at the hospital. I wasn't told by a staff member it was an issue. I asked the Nurse Practitioner a question about the news and asked if it would put [REDACTED] at extra risk being here. She said, no it's fine. She went away but then came back saying [REDACTED] was well enough to go home. It gave the impression that anyone who didn't need to be in the hospital was well enough to be managed at home. It looked as though you were better being managed at home rather than being in that environment."

Q So, when you asked about it, she said it was fine, but then, very shortly after that, you were discharged home? And what was your perception of why [REDACTED] was being sent home at that time?

A It came across, because I was asking questions whether it was safe for [REDACTED] to be there, that in actual fact it wasn't and that's why they wanted him to go home, because – although he had treatment to still have – he could be put onto an oral version of it and he could be sent home with that.

Q Okay. And I think you say in your statement that [REDACTED] subsequently spiked a temperature on the 10th of February 2019, and he was admitted again to the children's hospital, and I think you say you think it was Ward 2C, is that right?

A Uh-huh, yes.

Q This is around about paragraph 55 of your statement. Then, I'm sorry, could I take you back to-- it's paragraph 84, you describe this event further. I think you say you had some concerns about the cleanliness of this other ward, is that right?

A Yes.

Q Can you tell us about those concerns?

A When we were on that ward, and I had asked for some bedding for the parents' bed that was there, and I was handed a blanket that had blood stains all over it.

Q Did you did you say anything about that to the staff?

A I can't remember if it was a nurse or an auxiliary staff member. It was whoever came in the room next. I just said to her that they've given me this blanket and it's covered with blood stains, can I get something different?

Q And I think you also say you had a concern about the staff not wearing masks.

A Yes, so when [REDACTED] was on that particular ward, it eventually came back that [REDACTED] had the flu. And as soon as that diagnosis came in, the staff members then started coming in with masks on and aprons on. But before that, like literally hours before that, there was people coming in and out his room with no masks, no aprons, nothing. Surely, as a precautionary measure, they should have had these things on.

Q Okay. Ms Young, we're approaching the end of your evidence, but before I move on to ask about the impact of all of this on you and [REDACTED], I want to ask you some questions about communication at the hospital, first of all, and the paragraph reference for this is 104.

Now, I think you say in your statement that you felt communication about your son's treatment was good, is that right?

A Yes, so before and every

round of chemotherapy that [REDACTED] had, his consultant would come in and go over-- She gave me a printout of what his kind of protocol would be, and before each round started, she would come in and explain really clearly exactly what medications [REDACTED] would be getting, what they were for, what effects it would have, if any, on [REDACTED]. And so, yes, it was quite clear----

Q Okay.

A -- in that sense.

Q Okay. And generally, how did you feel about other aspects of communication?

A Very poor.

Q And how do you describe that at-- Sorry, Ms Young, I was going to ask if you'd describe that at paragraph 107. The first sentence of that paragraph.

A Yes, like "night and day" compared to communication with his medication and his treatment. We were fully informed about what treatment [REDACTED] was going to be having, what medications he would have, and with other situations – for example, the room moves – we were not informed at all; it was just, "This is what's happening, and it's happening now."

Q I wonder if we could just break that down a bit and just reflect

on how you felt about communication in relation to, firstly, preventative antibiotics?

A We were never told why he needed to be on these medications. You trust the doctors and nurses, that they know what they're doing, and when you're told by a doctor that your child needs to be put on a certain medication, you trust that it's for a good reason. Obviously, we've now found out that these medications were because of the issues with the water, and it was to make sure that he didn't get any serious infections, but we were never asked if we wanted him to be put on it and we were never told what they were for at the time.

Q Okay. And I think you've already indicated how you felt about this, but how did you feel about communication about the frequent room moves on the ward?

A It was very frustrating. And, as I said before, we were living on the ward, we were there for six months as an inpatient. [REDACTED] gathered up so many toys, clothes, gifts – you name it, he had it. And to be moved rooms on a daily basis, it was such an upheaval, not just for [REDACTED], but for me, and for the nurses as well.

Q And I think you've indicated that you found the lack of

communication about that frustrating.

A Yes.

Q And how did you feel about communication about the water issues at the hospital?

A There was none. Any information that we found out was through the media or through talking to other parents.

Q Okay, and then communication about the pigeon droppings incident in January 2019?

A Again, it was through the media that I found out, and even after asking a staff member about it, we were still told there's nothing to worry about.

Q And, Ms Young, you say in your statement that, at the beginning of your son's treatment, you were warned that it might be infections that would make them very ill. Given what you've told us today, how would you assess the communication about the infections your son suffered?

A It wasn't until I've read his medical records that I've found out what infections he's actually had while he's been in hospital. So, there was no communication with the staff, whilst we were an inpatient, as to what they either suspected was going on or came back positive for. There was no communication.

Q Okay, and how would you assess communication relating to infection risks posed by the hospital environment?

A There's no communication with that either.

Q And overall, how did you feel about hearing things secondhand from the media?

A It felt like we were just not worthy of being told what was happening. We were living on that ward, and we should have been the first port of call. Any issues that were happening, the parents should be told what's happening. We shouldn't have to hear it through watching the news or reading a newspaper; we should be the first people that find out about it, and we just weren't.

Q And would you have preferred to be armed with some information direct from the hospital before you saw stories in the press?

A Yes, because then we would know what we were facing. We would know what the possible risks of those situations were.

Q Okay, Ms Young, to conclude your evidence, I'm going to come on and ask you to reflect on the impact that all of this had on you and your mum and on [REDACTED]. I'd like to start with you and your mum.

Your son was going through punishing treatment for cancer, which clearly had an effect on you and on your mum. What additional impact did all of these other issues have on you both?

A It was hard enough being in the hospital at the time going through what we were going through without all these extra things being added in. It was hard on my mum to see her grandson going through gruelling cancer treatment and then hearing everything that was going on in the news. We couldn't have done it without my mum being there, she was a huge support to both [REDACTED] and me. I didn't want to leave [REDACTED]'s side at all, she sort of did all the running around for me: she would go and get me something to eat, something to drink, she would do our washing; she was just a strong support for us and she was having to then deal with-- I mean, she would complain to the nurses about different things that had happened. I didn't really want to speak up about it, I was kind of worried that, by speaking up, we'd be treated differently. My mum wasn't scared to do that. She would just say it how it is, basically. But, yes, we couldn't have done it without my mum being there.

Q Okay. And what was the additional effect on [REDACTED] of

all of this?

A [REDACTED] has been left with a number of issues since being discharged from hospital, mainly his mobility. He was stuck in source for quite a long time with different infections, and he wasn't able to walk up and down the ward, so he was pretty much stuck in his bed, on his iPad; in the room there's nothing else to do. And he was a tiptoe walker before he was admitted to hospital, but since being in hospital, with being bedbound for so long, and some of the medication that he's had, he's been left with mobility issues. He has to wear splints on both of his legs, and he uses a wheelchair for sort of long-distance outings.

[REDACTED] also suffers with really bad and separation anxiety. He does not like being away from me at all, and he's also being tested for ADHD at the moment. We don't know if any of that would have happened anyway or if it's as an effect of everything that he's been through. I suspect a lot of it is through being in hospital for such a long time and having to go through the treatment that he went through. Yes, it's been a tough experience for him.

Q Thank you, Ms Young. That brings me to the end of my

questions for you. I understand you've prepared a statement that you'd like to read out. Would you like to go ahead and do that now?

A Yes, I'm going to mess one part of it because we have discussed it already.

Q That's okay.

A I would just like to take this opportunity to thank you for allowing me to be here today and tell [REDACTED]'s story. I would also like to take this opportunity to thank all of [REDACTED]'s medical team, from the doctors, nurses, play therapists, cleaners, reception staff, dinner ladies, and anyone else I may have missed. In particular, [REDACTED]'s consultant, Dr Chaudhury – [REDACTED] would not be here today without your help and support throughout the hardest time in our lives, and I thank you from the bottom of my heart for giving me my little boy back.

I would just like to reiterate that, by me being here today, I'm in no way blaming the staff at the hospital for the mistakes that were made, I'm simply blaming the circumstances. The circumstances the nurses were (inaudible) meant they were under immense stress and had an added workload with not enough staff. They were just as much in the dark as we all

were with the situation with the water and were doing their best in an already difficult situation.

I'd like to mention that, in my opinion, this hospital should never have been allowed to be open and someone needs to take responsibility for that. These children that are being treated in the hospital deserve better; us as parents deserve better for our children. You do not go into a hospital with a serious illness and expect to have to worry about basic human rights. God forbid [REDACTED] was to ever relapse, I do not want to have to take him to that place and have these worries again. I want this to be a safe environment for everyone – not just the children, but the staff as well.

Q Thank you. Before we conclude, Ms Young, is there anything else that you would like to say that have not already said today?

A No.

MS ARNOTT: Thank you. My Lord. I do not have any further questions for Ms Young.

THE CHAIR: Thank you very much, Ms Young. Thank you for providing your written statement and thank you for answering questions this afternoon and thank you for your closing statement. That's now the end of your evidence which will be part of

all the evidence to be considered by the inquiry. Thank you very much.

A Thank you.

(The witness withdrew)

THE CHAIR: I think our technical team will perhaps close the link-- may have done so. Well, that closes the proceedings for today and, obviously, for this week. I understand we'll be able to begin again at 10 o'clock on Monday.

MS ARNOTT: Indeed, my lord.

THE CHAIR: Right. Thank you, thank you to everybody, and we'll see each other on Monday at 10.

(End of Afternoon Session)