SCOTTISH HOSPITALS INQUIRY

Hearings Commencing
20 September 2021

Day 2
Tuesday 21 September 2021
Morning Session

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10:00

THE CHAIR: Good morning, everybody. Now, Mr Duncan, are we ready for our next witness?

MR DUNCAN: Yes, my Lord.

THE CHAIR: You can bring in Mrs Gough, please. (After a pause) Good morning, Mrs Gough. Good morning. I trust you are comfortable there.

A Yes. Thank you.

THE CHAIR: As you know, you are going to be asked some questions by Mr Duncan who I think you've met.

A Yes.

THE CHAIR: Now, the first step is I think you are prepared to take the oath?

A Mm-hmm.

THE CHAIR: Can I ask you, just sitting where you are, raise your right-hand and repeat these words after me.

GOUGH, Mrs COLETTE

(Sworn)

Examined by MR DUNCAN

THE CHAIR: Now, the plan for the morning is I would probably, as a matter of routine, take a break for coffee about 11.30. It depends how -- it depends where we are, but if, for any reason whatsoever, you would just prefer to take a break before then or

after then, just indicate to me and we will break.

A Thank you.

THE CHAIR: Right. Now, Mr Duncan?

MR DUNCAN: Thank you, my Lord. Morning, Mrs Gough.

A Morning.

Q Mrs Gough, can I just begin by having you confirm that you are Colette Gough and that you live with your husband and three children in Renfrewshire? Is that correct?

A Yes, that's correct.

Q And you are here today to give evidence in particular about your son who I think is currently ten years old?

A Yes is.

Q And in particular about treatment that he received at the Royal Hospital for Children and the Queen Elizabeth University Hospital in 2018 and 2019. Is that correct?

A Yes. That is right.

Q I think it would make things simpler going forward if I refer to those as, "The children's hospital", and, "The adult hospital", but I think we should understand that they are both on the same campus. Is that correct?

A Yes.

Q Now, you've provided a detailed witness statement about your son's experiences and indeed your own, and am I right in understanding that you are content that that forms part of your evidence to the Scottish Hospitals Inquiry?

A Yes, I am.

Q But nevertheless you've come along today to answer some more questions about some aspects of that. Is that right?

A Yes.

Q Do you have your statement near to you?

A I do, yes.

Q At any point if you want to go to it to clarify anything, just say so, and we have got support behind us, in particular, I think Ms Ward is going to be helping us, and we will look at parts of your statement as we go through it, and can I also just emphasise what his Lordship has said to you about having a break. Don't be shy. If you feel you want a rest for whatever reason or if you feel you want to go and think about things, just say so. You are our only witness for today, so the day is yours, as it were. We will start with a bit of background. Tell me a bit about your son.

A [redacted] is amazing, what he has been through, how strong and resilient he has been. He is a bouncy, noisy -- was at the time of treatment -- seven-year-old who never sat still for any length of time unless his head was in a book or building Lego, and he is a gentle wee soul who is very emotional and very friendly and would walk up to random strangers in the park and say, "Shall we play?" he was that kind of kid, and he still is that kind of kid to some extent, but he has been battered and bruised a little now. He has grown up a lot in the last three years which I think any child going through cancer treatment does. He really is a credit to us, and we are very proud of him.

Q He's the eldest. Is that right?

A He is, yes.

Q Is it two sisters?

A Two sisters who are as noisy if not noisier, Ann and Elizabeth, and they have been amazing and resilient through this whole process because when one of your children becomes ill, they become the focal point, and our life, or that whole year of 's illness, revolved around him and they were the afterthought because they had to be, and they just rolled with it and we did our best to always include them where we could, and to tag team so that one of us had the girls and one of us had [redacted], but they were a little unit themselves, and they're very close and looks after her wee sister and her wee sister fights against being looked after constantly, Miss Independent.

Q And I think you've already given us an indication of the sort of things that [redacted] is into -- reading, Lego. Are those his two passions, as it were?

A As it were, yes. When he was in hospital, grandad brought him -- which we love grandad for this -- brought him in a little box of dollies to paint. I keep calling them dollies, they're not, they're mini figures, so it was a kind of role playing game where you paint the little figures and then you battle them, so he doesn't ever battle them but he sits painting them, these little figures, and it was a good thing to do because he could sit still to do it, so even when he was feeling rough, it would still focus him and draw his attention, and take his mind away from where he was, and that's a very expensive hobby that grandad has introduced him to, which we've been buying into for the last three years, so he's brilliant. He really is amazing. He's a smart kid and he is aware of things going on around him. "He's biddable", quoting my mother there. He is so biddable, even when he doesn't want to do something you can talk him into it and you can rationalise with him and explain to him why we have to do it, an even at the worst parts of his treatment, even when he didn't want to go, well, we have to go [redacted], this is it. Okay. All right, mum. There was only one occasion where he said no, and that was it. But I'm sure we will come to that later.

Q Maybe we should now move on to think about all of those aspects. Let's start off, then, with just trying to understand, really, the history of [redacted]'s illness and when it began and what happened after that and maybe if you just want to tell us a little bit about that.

A Sure. When we were on our summer holidays, he reported from the bathroom that his wee was a funny colour. "Mum, my wee is a funny colour", oh, that's all right son, he had beetroot for dinner last night, don't worry about it. It will be fine, and then the next day, "Mum, my wee is still a funny colour", and when Cameron observed that, he went in and had a look and he said, "Oh, that is a funny colour. I think you should take him to the doctor right now", so it was pink, and we went to an out of hours in the local community hospital in Annick, and she suspected a urinary tract infection but said, "That's not common for wee boys, common in wee girls but not wee boys so when you get home speak to your GP and have this followed up because that shouldn't be happening". He had an antibiotic over that weekend and then the following four, five days later, again, there was blood in the urine, and so we phoned our own GP and he was able to say, "Come in tomorrow", so we packed up and went home the next morning, so that we could go into our GP and he gave him another antibiotic, a different one over that weekend, just in case it was a UTI or a kidney infection, but he also scheduled us to get blood work done which we couldn't do on the Friday afternoon because it has to be done in the morning to go to the lab, so we were booked in first thing on Monday morning for blood work. That came back showing that he was anaemic and so he sent referral to the ultrasound department for a scan, and also the renal department for a kidney investigation.

Q And where was that?

A That was at the RAH, which is the Royal Alexander Hospital in Paisley. The renal appointment never came through, I'm assuming because we had already then jumped on to the ultrasound, so the ultrasound appointment took three weeks to happen, and in that time the blood in

his urine was more frequent and more prominent. We had gone from being pink to being bright red, and it was quite frightening for him. There was not much that the doctors could do other than wait for this diagnostic scan.

Q Was it frightening for you by this point?

A It was a little concerning, but to be honest at that point I was still thinking kidney infection. I was thinking kidney issue. As a child I had a wee kidney issue, I had investigations and it was all solved very easily, so on the Monday -- we had gone to stay with my mum and dad because the kids were doing a summer dramarama camp and it was near my mum and dad's house so we had gone to stay at mum and dad's house while Cameron pulled our bathroom apart and did some redecorating, but he came to meet us at the hospital for that scan, and the ultrasound scan showed a mass on his kidney and that was all we were told at that point. She said, "I'm going to phone your paediatrician", and I said, "Well, it is our GP", "I'm going to phone your GP right now, go home and pack a bag, you are going straight to the sick children's hospital, and someone will see you today", so we went home and packed a bag. To back up a little, on the Sunday at my mum and dad's there was a bit of rough and tumble, my sister was there with her kids, so it was cousins playing in the garden and | bumped his side and he went green and really wasn't very well and he's a bounce and keep going -- if he falls over, he bounces and he gets up and runs away. For him to cry or him to get upset about an injury means he's really injured, and by tea time he had no appetite and overnight that Sunday night he was vomiting through the night, and I thought, oh, sickie bug, all right, what's going on now, but the fact that he had bumped that side, now hindsight is a wonderful thing, he had bumped the tumour, he had bumped the kidney that was cancerous at that point. Hindsight is a wonderful thing, isn't it? Could have, should have, would have. So we went to sick kids and we had a letter from our GP, we ran in and picked up a letter to take us straight through A&E because when we phoned the GP he said, "I don't know which department you are being referred to, is he still being sick, yes, take him straight to A&E, just go. Don't sit and wait for someone to phone you", so we sat in A&E waiting to get admitted --

Q Just to interrupt, that would be A&E in The Children's

Hospital?

A In the Children's Hospital. Yes, and we were escorted through to the CDU, which is the A&E building is separate, if you like, from the oval of The Children's Hospital. The A&E rooms are square. Once you go into curve-y rooms you are in The Children's Hospital, so we moved into the CDU and that's where we first met Dr Ronghe who was our oncologist and I want to give credit to the ultrasound technician that day because her referral straight to the right guy meant that the first doctor that we met in the oncology suite was the expert in Wilms tumours.

Q I think this is 30th July --

A Yes.

Q -- give or take, and you were introduced to a gentleman who is an oncologist?

A Yes.

Q Presumably you joined certain dots at that point.

A Alarm bells are ringing, and I was still in the zone of, “Well it might not be, it's just a mass. They need to do magic things to find out if it is cancer". We hadn't said the C word at all at that point, and in fact nobody said the C word for the first few days. That's quite a scary word. As soon as that word is out there it becomes real.

Q Was that partly because they too were still investigating?

A No. It was more that they wouldn't say that word in front of the child until we said it in front of the child. They took our lead on that, and it was more about being aware of what you say in front of the children. They were very aware of that, especially in those early stages. They treated us very much with kid gloves. They are the experts at this. We had never done it before, but they have done that a hundred times.

Q And that's including even in relation to how they communicate these issues?

A Mm-hmm. So particularly that first day, they said, right, well, we want to arrange an MRI and we don't know how long that will take. It may be today, it may be tomorrow, but until then, we will transfer you upstairs into the Schiehallion Unit. Now, we had never heard of Schiehallion. We didn't know that the oncology suite was called, "Schiehallion", and actually, unless you are in that circle you don't know about Schiehallion, and so our way of getting that across to [redacted] was, oh, we are getting an upgrade. We are going first-class [redacted]; we are getting an upgrade. We are going upstairs where they have got Netflix. Now, Dr Ronghe said the magic word, they have got Netflix. We didn't have anything like that in our house, we are old school, we have CBeebies and that's it, so he was a bit excited by that and that buoyed him a little, that we were going upstairs to a fancy room, and they managed to arrange an MRI that afternoon which confirmed the diagnosis that it was a kidney tumour. Now that evening when they came to speak to us and say, "We have confirmed that it is what it is", they didn't say the C word and I said, "Are we there? Are we calling it that?" And it was a nod from Anne Marie who was the junior doctor at that point, and that was -- I can only liken it to -- I have never done drugs, I can say that with my hand held high -- I can only liken it to that scenario in Trainspotting where Ewan MacGregor falls into a hole. That's what it felt like. It just felt like oh, now what, because it's completely unknown, and the fear and didn't sleep a wink that night, just lay thinking, oh God what are we going into, I have never prayed so much in my life, how bad is this going to get, how bad is it going to get. Is this terminal, because at that point we didn't know, and as soon as you say the C word, immediately the next question is, "Is it terminal, is this it, is this where we are going here", and we had to have a CT scan the following day which would checkout his lungs, so a Wilms tumour -- or what he was presenting with, they were assuming was a Wilms tumour because in 80 per cent of cases of this presentation it is a Wilms tumour, so rather than taking the time to do a biopsy and wasting time doing a biopsy, they assume it is a Wilms and they start treating for a Wilms because it gets at it quicker. The most common development of a Wilms tumour is additional growths in the lungs, so that was the next stage. That's stage 2.

Q Hence the CT scan?

A Hence the CT scan to check the lungs. There was no transferring to the lungs so that was good news, and so that immediately put us on to a protocol of treatment which meant he would have four weeks of chemo and then have surgery to remove the tumour and the kidney, and that was the message that I had to sit and type to my family that night, say, right, here we go. That was the first message that I sent out to everybody because I couldn't -- I was just messaging my mum and saying, “Mum, you know, you've got -- you will need to keep the girls.” That's fine, you've got the girls. “They're sorted, that's fine, don't worry about them, be where you need to be,” and my sister and my mum just took over the girls. I didn't need to worry about them at all for the next four/five weeks, and the message that I sent out to -- I'm one of seven, I have got lots of brothers and sisters and they were all not messaging me. My mum was just the hub of all that contact and all that information at that point, and that's the way it works in our family. When something happens, send it to the mother and she will spread the word out, and so I was just messaging her and saying, right, this is where we are at, we are better than we were last night, it's not so unknown, but it's a Wilms tumour, we are looking at four weeks of chemo, tumour out, and then we take it from there.

Q What was it that made it better than it had been?

A It wasn't in the lungs. It hadn't spread.

Q Was the provision of that information?

A Sorry.

Q There was the provision of that information? You knew more?

A Yes. Everything was so unknown that first night. I had also had a day in the ward with other parents, so I don't know if you've ever walked into a children's cancer ward. First walk in takes your breath away because it's the first sight of these beautiful bald-headed children who are scooting up and down the corridor on their -- the drip stands which are on wheels, and some of them are sitting on them and the parents are wheeling them around, and some of them are on little scooters and ride-alongs, and some of them are walking up and down playing Playstations.

They are being children who happen to have cancer, and that's a big learning curve for us to be able to see how they had normalised it, and how they were managing to maintain a life in this space that is the horror of all parents, the worry of that, the anxiety of that, so that first morning I went along to the parents’ room. We got a bit of a tour that first evening, saying, you know, “This is your room and stay in your room, you are not allowed to go into other people's room.” We were handed a booklet this sort of size with protocols for keeping everybody safe on that ward, rules like we are not allowed in other people's rooms, that we weren't allowed lots and lots of visitors that we had to be mindful of the fact that the children there were immunocompromised, that we had to

keep the place tidy, that we had to always do the magic hands, which is the hand sanitiser as you walked in, which we are all so familiar with, but at that stage that was new to us. In the play room, how everything was sanitised, everything you touched you then had to sanitise before you put it back, that the kitchen had to be kept clean and tidy, that anything that you put in the fridge had to be labeled clearly, you weren't allowed shellfish, you weren't allowed eggs because those could breed a bacteria that could injure the children that were on the ward.

We were like, oh right, well, we don't want to make anybody else sick, so we were following every single rule and guideline that they were giving us, and that first morning I went along to the kitchen to make myself a cup of tea, he was still asleep, and that was the first time that I left the room. It was the first time I left him alone, and I went into the parents’ kitchen and I sat down and everything came out. I just burst into tears, and I can't believe I'm here, oh my God, the panic was bubbling up all night and it was just, oh, I can't believe we are here, I can't believe we are here, I can't believe we are in this ward, I can't believe what we've got ahead of us, what have we got ahead of us. Are we going to lose him, and if we are going to lose him, how awful is it going to be? All of those thoughts racing around your head, and a granny of another child and a mother of another child came in to get their morning cup of tea and the support that they gave me -- they know who they are so I'm not -- I don't want to say their names but the support that they gave me that morning was invaluable, because they reassured me that I was in the right place, the best place for my child. The top tip was, "Right everything down that the doctors tell you", because you are so overwhelmed -- especially this week, you are so overwhelmed with the learning curve that you are about to be on, write it all down because you won't remember it, so write it all down, which is the reason that I kept a diary. I never been a diary writer up until then, and it wasn't a “dear diary” sort of diary, it wasn't a Bridget Jones diary. It was, here is how he was today and this is the meds that we are on at this time and this is the reaction that he had to them and keeping track of all that which then helped us when we were doing hand over of care with each other throughout his treatment, but the support that those parents gave me that morning was a life saver for me. It really was.

Q This is literally morning one?

A Morning one, first night in the ward.

Q Let's just go over some of that again, just so we've got an understanding of the timeline on this. You arrive at A&E and then you go into somewhere you described as the CDU which I think is the --

A Clinical decisions unit.

Q And then upstairs to something which you discovered was called the Schiehallion Unit, and you had never heard of that before. Is that right?

A No.

Q And at some point, you did discover what that was, and what was your understanding of what the Schiehallion Unit was and what happened there?

A It is an oncology hematology unit, and it is for treating children with cancers.

Q And [redacted] was admitted to a particular ward within it to begin with. Is that right? Would that be Ward 2A?

A 2A is the admission -- the long stay ward, is that the right phrase? 2B is the day care ward. We were then -- we were admitted that first time for, I think, ten days -- I will have a look at my timeline -- we went in on the Monday, we went home the following Wednesday, if you can do that sum in your head, and towards the end of that stay we were given a tour of day care which -- Ward 2A is one of the horseshoe shaped wards, and 2B is across the corridor and it is a straight ward on one of the long edges of the oval.

Q Okay. I wonder, Mrs Gough, if it might help everybody if we actually had a look at your statement, because you've got some very detailed descriptions of the hospital and its infrastructure, and Ms Ward, I think, is going to help us with this. Ms Ward, I wonder if we could go to Bundle 3, please, and I think it would be page 90 which will take us to Mrs Gough's statement, and I'm going to ask you to look, please, at paragraphs 15 and 16 --

A Sure.

Q -- of your statement. Okay, now you've got those in front of you. Mrs Gough, would you be comfortable just reading out what's there --

A Sure.

Q -- to avoid you having to duplicate it?

A Say it all again: "Wards 2A and 2B are both in Schiehallion

which is the oncology ward for kids. 2A is the inpatient ward and 2B is the day care ward. 2A is one of the horseshoe wards so it is on the end of the hospital in a big curve. When you go into it you walk round a big semicircle and all the rooms are off either side. There were 20 something bedrooms on the ward. As you walk in the door the first rooms are training rooms, and then the parents' kitchen, and as you walk further along you come to vac rooms which are rooms that are set back from the corridor. Those rooms have a double entry system to get in and are for the kids that have had transplants. They are on a heightened level of cleanliness and infection control management. These vac rooms also had monitored on the walls outside which were pressure gauges. They were negative pressure rooms. I have no idea what that means, it was just something I was told by the staff on the ward. There were maybe four of these rooms. After those rooms it was the play room on the right, it had lovely big windows and colourful pictures, and that's you into the curve area now so the rooms are all a funny shape from the outside. They have all got an arched wall and there was the nurse's station, and behind that there were two-bedrooms that were set back. Around the corner was the utilities and bedding room where you could go and get extra bedding, pillows, things like that and extra sheets, and then the bedrooms carried on around the curve and as you were coming off the curve at the other end was the Teenage Cancer Trust area which was the area for older children. They had a play room that was just for teenagers and was set up with Playstations and gaming chairs and things like that. Then you get to the other end of the horseshoe and there was an exit door to go back out towards the lifts there".

Q Thank you. If you just stop there. Now, you refer there to standard rooms and vac rooms. Vac rooms, are we to understand those as essentially being rooms where there was effectively a lobby before you went into the room itself?

A Yes. That became the term that we used when it was the door to go in and then a lobby area where the staff could wash their hands and you could leave luggage and things like that outside, but also in this area and space there was the ones with the pressure gauges as well, so all across The Children's Hospital in each different ward there are a few vac rooms which are isolating rooms that have that lobby area, but here in Schiehallion there was additional rooms that had pressure gauges as well. Not all of them had that pressure gauge system.

Q I see. Thank you. Now, helpfully in your statement you also give us a description of what a standard room looked like, and again I think it might be quite helpful just to actually look at what you say in your statement. This is just a little bit further on from where we are at the minute, Ms Ward. It is paragraph 21; I think it is at page 92 in the bundle.

A Would you like me to read that as well?

Q Would you mind?

A Yes: "In terms of the bedrooms themselves, they were all standard. You walked in and there was a sink on the right-hand side, then a bedside cabinet, then a bed, then on the other side a bedside cabinet and then a wall unit which had a fold down bed for the parents. It had to be put away. There was a big purple reclining chair which you had to move out of the way to put the bed down. There was a wardrobe unit and a chair with two arms and a high back. There were also stacking chairs that you could bring in if you needed. We had one of them in the room as well so that there was a chair for us all to sit on, so we weren't sitting on the bed. We were told by staff that visitors shouldn't sit on the bed for infection control. As his parents we were allowed in his bed and we spent a lot of time in his bed with him, sleeping and comforting him. Then there was a bathroom off the bedroom with a toilet, a sink and a shower area".

Q Thank you. If we can put that to one side now please, Ms Ward, can we please go to Bundle 2 so that we can have a look at the photograph of a bedroom? And if you go, please, to page 25 in Bundle 2, and if you are able to see that, Mrs Gough -- I don't know if it has come up on your screen yet --

A There we are.

Q It is photograph 12, albeit it has got a cot in it, is that similar to the room that [redacted] was in?

A Yes. Yes. There's not as much furniture in there as there would be usually. There wasn't a lot of space.

Q It looks like a reasonably large room from this photograph. Is that not your recollection?

A Yes. It is an individual room. By the time you have a full sized bed, there's not a lot of space at the bottom, if you can imagine that the foot of the bed and the wall, you would have space to have -- if you had the Playstation with a TV sitting on it, for example, there would only be space to walk past. It wasn't a very big area.

Q If we just look at some details in the room, perhaps. Towards the window, the brown unit, is that where the fold down bed came from?

A That's the pull down bed and I want to differentiate between a fold down bed and a pull down bed. The pull down bed is a flat mattress. It doesn't get folded, so tat is the length of the mattress and when you pull it down a lovely big foam mattress is there that gives you some lumbar support. A fold up bed gives you none.

Q And is that -- was it fold-out beds that you experienced elsewhere in the hospital?

A Yes. Yes. As soon as you leave The Children's Hospital area there are no pull down beds, and in fact in the CDU unit, which is in the bottom floor of The Children's Hospital, there aren't pull down beds because you are not expected to stay there. It is an admission ward.

Q Okay, and so we would then imagine next to that brown unit where the pull down bed would be, there would be a bedside cabinet is that right?

A Yes.

Q And then I think above that we see some sort of arm that's attached to the wall with a screen on it. Is that right?

A Yes. That is the TV which [redacted] loved. That was the Netflix. That was the wonderful Netflix that Dr Ronghe enticed him with, and The Children's Hospital, the TVs are probably the same size as this screen that we are using just now, and in the adult hospital they're probably the size of the laptop -- sorry, I have forgotten your name -- that this lady is using, and that was the difference between the adults and the children's.

Q Did the TVs work?

A Sometimes.

Q Sometimes they didn't?

A Sometimes they didn't. Yes, and if you got a TV to work, getting a remote that worked as well was always fun. We ended up packing batteries in our grab bag so that we could always put fresh batteries in.

Q And again, just looking at the photograph, if we can, towards the left-hand side of the photograph we see a doorway, I think. Do you see that?

A Mm-hmm.

Q Is the bathroom through there?

A Yes. It would be.

Q Okay. We can put that to one side now, thank you. Just pausing there, then, Mrs Gough, when [redacted] was admitted to Ward 2A, and indeed generally whenever [redacted] was admitted to the hospital, did either you or Mr Gough accompany him in his stay overnight?

A Always.

Q Did you do it turned about or how did to work?

A Only one parent was permitted to stay. We were told that on that first night, only one of you is allowed to stay which meant that first night I played the mum card and I said, "Well, I'm not leaving him, you will have to go home, Cameron", and also "You have to go home and put the bathroom back together" because there wasn't a functioning toilet in our house at that point, so we then kind of took turns about, really, and then when, later on in his treatment, we got into a rhythm of Cameron being the one that would take him in during a spike.

Q I think later in your statement, we don't need to turn this up, I think it is paragraph 175, effectively you describe how the family almost became two family units.

A Definitely. One of us had the girls, one of us had [redacted], and even when we were together, all of us, the five of us, one of us had the girls, one of us had [redacted], and it wasn't always discussed or planned, it was just that that was the roles we would take on, that one of us would always be keeping an eye on him, and when we were all together as five, quite often I would have the girls just because Cameron was really good at just touching forehead with [redacted] and that was enough to check his temperature, because you got really anxious about that all the time, and we were using like inner ear thermometers, but just a touch of the forehead, “Come here kids”, touch forehead, yes, he's fine, was enough. Cameron was kind of OCD about that.

Q I want to ask you some more questions about the Schiehallion Unit and I'm focusing really about the early stages of [redacted]'s care in August 2018. You've already given us a very vivid description of what your first impressions of Ward 2A were, and you've already touched on some of the aspects of the facilities. One of those was the parents’ kitchen. Now, again, for those who want the reference in the statement, it's paragraphs 22 and 23. We don't need to turn it up just now, but I wonder if you could just give us an impression, or a description, of the parents’ kitchen, what it was for.

A It was first and foremost a breakout space for parents. I have already talked about how that first morning it was the place that I went to to release the emotions that were building up. Couldn't do that in front of . I couldn't cry in front of him, I had to be strong for him, and so that was the place that you could go to have a breath and a moment to gather yourself to be able to go in and do the next bit. It was a place where, if other parents were there, you could make chit chat, but also other parents would respect the fact that if you were there just for a cup of tea and wanted to walk out and not stay and chat too, that was fine too, because everybody was fighting their own battle, or their own demons. The space itself had two large fridges, kind of American style fridges, the big -- and then a sofa and a TV on the wall which, if you could find a remote for, it was a miracle, a small table with a few chairs around it, and then a worktop space by the window and then a worktop space which had a dishwasher and a small larder fridge and a couple of cupboards that you could store things in if you wanted to, but in reality most of those cupboards sat empty, but there was always a bag of Ziplock bags and a big pack of white sticky labels and a few pens and a couple of big packs of wipes were always there, so whenever you brought food into the kitchen, you had to wipe it down, name it, date it -- with our name and the date -- before you -- and put it in a sealed bag before you could put it into the fridge, and that was to stop any cross-contamination.

Q Another aspect of the ward I want to ask you about is the play room. Could you describe that to us please?

A It was a curved room, so all windows on the corridor side and then it was in an arch going out towards the windows on the other side, and it had two large windows and a small bookcase filled with books and DVDs, and this wall here had lovely sensory machines to project light and bubbles and things for the smaller children. They had a lovely projector that would project lights onto the floor so the little smaller children could chase them like cats. They loved them. A container full of toys and pull out drawers with lots of little toys in them, so they were all sorted into, you know, the animal box for the animals and cars and things like that.

A couple of little tables with small children sized chairs at them, and then two large -- a whole wall of locked cupboards, and those locked cupboards had games, arts and craft supplies, activities, things like that, and to access that you had to have a play worker there because we weren't allowed to go into it for infection control, so there was always wipes, and there was always hand sanitiser, and plenty of plug points because when you came along with your child, if they had a drip machine you had to plug them in, otherwise the alarm would always go off.

Q Somebody who has been through the experience that you and your family have been through, the importance of the play room may be self-evident, but those of us who have not been through that experience, I wonder if you could maybe explain the importance of the play room?

A That's where the children got to be children again. They weren't patients. I am a mum of three but before I was a mum of three, a community artist, and my training is in using play as a means of therapy and a means of communication and a means of engagement, and that's what that room is. It's the safe place for them to go and be children again, and to interact with each other. I wouldn't say there was the same supporting each other that happened for the parents in the parents' room because they weren't aware of that level of need or anything. They were just kids playing and looking for engagement. [redacted] didn't want to play his mum at chess, you know, or anything like that. He didn't want to play games with me. He didn't want to sit and chat to me. He wanted to chat to the other kids, and it was a boon for us to be able to go along to the play room and get out of your room, and there was one night in that first fortnight, one of the other wee boys had been taken out for a wee -- off the ward time, he had been given a pass, this wonderful thing we heard about. Oh, he got a pass! He got to leave the building, that's amazing, getting to leave the building! He came back with a new DVD, and so he put it on in the play room, and we all sat like a little cinema watching on a screen this size -- sorry to point at you again, very rude of me -- a small laptop screen, which was a Playstation trolley, and that was us all sitting round this wee screen watching Peter Rabbit, and the chortling that happened at all the rude bits, at all the bits where Peter Rabbit did something that he wasn't supposed to do, they loved it,

and it was actually one of the nicest nights that we had in the ward because they forgot that they were sick. And even though the trolleys were still there with the chemo on them or the fluid bags still attached to the children and beeping in the corner, and the parents just, "Aye, silence the monitor, it's plugged in, it's fine, silence the monitor," and that bit there became invisible to the fact that they were sitting watching a movie together. The play room was essential.

Q You mentioned play workers at one point in your evidence.

A Yes.

Q So there were play workers who would come to the room? What was their role if it's not obvious?

A The play workers are funded by The Children's Hospital charity, and there's a play worker for almost every ward in the hospital I think. They would come into our individual rooms and, "How are you doing today, do you want a wee activity brought along", and each day they would have a focus that they would be doing in the play room, and if you weren't able to go to the play room to join in the activity they would bring it to you if they could. So that first week was the Harry Potter week and they were doing magic activities and down in the big atrium which -- the oval of the hospital has a central atrium, which is where all the day clinics come off of, and it is the waiting area, but they would also have events happening in there, and so that week was magic week, and they had shows happening, I think, with the Science Centre where they are doing explosive things on a wee stage down in the atrium. We didn't get to go down and see that because we were stuck in our room because he really wasn't very good that first week, but a magician came into our room and did magic tricks, close up magic right at the end of the bed, and he did a thing with hair bobbles on his fingers when he got them to jump on his fingers, so for the whole rest of that evening [redacted] sat there with hair bobbles trying to get them to jump around his fingers, and that was all from the play team trying to organise things like that.

Q I think in your statement you indicate it was quite substantial involvement in the Schiehallion Unit on the part of various charities. Is that right?

A Definitely.

Q And I think that's something that you are quite keen to speak about today?

A Definitely.

Q Tell us a bit about that?

A Chemotherapy is gruelling for anybody and anyone that has witnessed, and I'm sure everyone has been touched by cancer somehow in their families, anybody that has witnessed it knows that it is awful, and particularly for children because they're losing their childhood at the same time.

The support that's required is more than just medical support and we wouldn't have got through our journey as well as we did if we hadn't had the support from all the charities, so I have written some of them down so I wouldn't forget any of them. In that first instance, the CLIC Sargent team who have renamed themselves -- they have rebranded since then -- they're called Young Lives Versus Cancer, on our second day in the ward, so that second day where I'm sitting shell shocked and, “Right, okay, we are getting surgery tomorrow, and we are starting chemotherapy on Thursday, and what's all going to happen”, a wonderful lady came in and said, "I'm your CLIC Sargent socialworker". Now, the only contact that I have had with socialworkers up to that point has been in a professional capacity where I have been working with them to work with children, so to know that we had a socialworker working with us, first of all, it was an, “Oh, I have got a socialworker,” but she was there to support us in any way that she could, and part of that was -- she became the gift lady. Whenever she turned up she would give us something, and it would be things like -- the nitty-gritty of it -- "Are you signed off work? Do you need help to get signed off work? Do you need benefits put in place so that you can be off work in order to care for your child? This is a long journey you are going to be on, and so I'm here to support you while you are doing it", and she was amazing. She was on the end of a phone, gave us her phone number, gave us bits of paper, "Sign that, there you go, there's a cheque for £250 from Love Oliver who are a family who have been through this and who fundraise in order to support families at this moment, because you need to go downstairs and buy yourselves some dinner. You need to do 100 trips back and forth to the hospital, so suddenly you are going to need to pay for petrol and you are not working because you have to be there to care for your child", and it meant that we didn't need to worry about things like that. I can list them all. I want to list them all actually so that it is

a matter of record. Love Oliver, Team Jack, Logan's Fund, Calums Cabin, Abbey’s Sparkle, Molly Olly. All of them are named after children who died and were set up by their families to help the families on this journey because they have been through it. Every one of those children has left a legacy that has helped so many families, and there are still more happening, and that -- for us to know that they had been through it, and that they had carried this load and they knew from experience what was needed to help, meant that we were just okay, “Yes, uh-huh, sure, if you think we are going to need that, then brilliant, we will take whatever help we can get”.

Other ones that I'm sure we will come to again later on were C Class and the Les Hoey Dream Maker Foundation who were not set up by families who had lost children. They were set up by families who had survivors, and they still know the journey that it takes, so just because your child survived doesn't mean that the journey was easy. It doesn't mean that the chemo was easy. It doesn't mean that the battle was easy. It doesn't mean that it's over, either. Cancer in children is not ever cured. There's always that, “What if it comes back? What if we relapse? And that's something that we have to manage over the next -- the rest of [redacted]'s life.

Q Mrs Gough, I noticed that today you are wearing a gold ribbon, and Mr Gough was wearing one yesterday, and I neglected to ask him about it, so I will ask you about it. What does the gold ribbon signify?

A Once you know, you know. The gold ribbon is the ribbon that we wear to raise awareness for childhood cancer, and everybody knows about the pink ribbon -- that has had wonderful publicity -- but not many people know about the gold ribbon, and you only know it once you've been in the world of it. September is Go Gold month where we raise awareness of childhood cancers, and the fact that not enough research is done to cure childhood cancers. The treatments that the children receive are based on adult treatments, and they're harsh. They are harsh treatments, and once the children get all this chemotherapy, the side effects that they're left with, they're left with for the rest of their lives, and they have to live with for the rest of their lives, so we need kinder treatments, and that's what the go gold is. It's about raising awareness of the battle and also raising awareness of the symptoms so that people catch it

quicker. Spot the symptoms in your child and go to the doctor. I called it beetroot and it was cancer.

Q Thank you. I want to go back now to think again about your experiences on Ward 2A again, just thinking about the early period of [redacted]'s care, and it's just really to allow us all to have an understanding of how the Schiehallion Unit worked, and one of the things that you talk about in your statement is infection control, and what I want to do again, if I might, is just take you to your statement, because you've got some very detailed evidence on this?

A Sure.

Q And there's no point in duplicating it, so Ms Ward, if we could go, please, to bundle 3, I think it is at page 91, and it is paragraph 17 and paragraph 19 of Mrs Gough's statement. Have you got that in front of you?

A I do.

Q Good. Would you mind doing the honours again?

A Read it? Just as well I trained in drama, you know: "When [redacted] was an inpatient on the ward we were not allowed in anyone else's room. That was very clear very quickly. We became like parents chatting over the back gate and would stand at the doors chatting to each other. The children would go up and down the corridors talking to each other and playing with each other. This was all to do with infection control and there were several protocols in place.

We had to use hand sanitiser as soon as we walked in. We called it magic hands. There was a restriction on the number of visitors allowed. You were only allowed two visitors in a room unless it was siblings. The staff said to try and keep visiting to a minimum just for traffic going in and out of the ward. In the parents' kitchen everything had to be cleaned before it was put into the fridge. We had to make sure that everything was single use. You weren't allowed to leave open food sitting. Edie, who was the domestic there, she was one of the staff who wore green shirts, managed the parents' kitchen. When I met her that first morning, she gave me the lowdown on how the parents kitchen worked and keeping everything things and the things that weren't allowed in the fridge. You weren't allowed eggs; you weren't allowed seafood. Everything had to be in date. Anything that was out of date was binned. Anything that came in that wasn't sealed from a shop you had to put the date on it, and it had to be binned the

next day. If you had cooked something at home and brought it in it had to be used that day. Children had to be given sealed food and if they opened a carton of juice and didn't drink it, you had to bin it and give them a new one".

Q Can we just pause there? I wonder if we could just scroll down, Ms Ward. Would that be possible? Thank you.

A "We were told not to worry about the waste. We had to clean everything down in the kitchen after we have used it. We had to use the dishwasher for dishes and if you were washing dishes in the sink you had to use the hot, hot water and the soap and then you had to rinse them with bottled water. We had to use bottled water in the kettles and bottled water to drink for all of us, especially the children".

Q Okay. If we just stop there. Again, Ms Ward, you can put that to one side. Thank you very much. So, just so we understand that rules included: you are not allowed in each other's rooms, hand sanitiser, restrictions on numbers in rooms, yes? There's a regime around cleaning of the parents' room. What about the playroom? Was there a regime about cleaning in the playroom?

A Yes.

Q And, I mean, I think you do say this elsewhere in your statement, I mean, the standards of cleanliness overall in what I would call, "The old Schiehallion Unit", were what?

A Gold standard. Gold standard. We were astounded and we very quickly upped our game to be at that level.

Q And one thing I'm going to come back to later that you mentioned just at the end of paragraph 19 about bottled water being used, why was this?

A There had been an issue with the water supply. "Oh, did you not hear about it? It was on the news". We weren't aware of it because we weren't in the circle.

Q So, I mean, just thinking about the very beginning of your experiences in the Schiehallion Unit, were you made aware at the very beginning of that process that you should be using bottled water?

A Yes.

Q Was there any explanation as to why that was?

A Not from any member of staff. Only from other parents, "Oh, there has been an issue in the past with water".

Q And who was it who made you aware that you should be using bottled water?

A That first morning it was Edie, the auxiliary.

Q I want to move on, then, to think about the evidence that you give about the description of the care that [redacted] received when he was on Ward 2A, and I suspect you would anticipate, once again, I'm going to ask you to read a part from your statement.

Ms Ward, could you please take us to page 95 of Bundle 3? I want to look on this occasion at paragraphs 33-35, so beginning on page 95 and then scrolling down to the next page once Mrs Gough gets to paragraph 34?

A "There were a lot of nurses on the ward. I don't know if we were one-to-one with the nurse. It was maybe one nurse looking after two or three children, but the staff did tell us the ratios were much higher in Schiehallion because the children did need more care. There was a nurse near us whenever we needed them." Especially in that first -- just to add that -- especially in that first fortnight: "When you pushed the buzzer it was the same nurse that came every time. There was always a specific nurse keeping an eye on the buzzer in our room and there was always someone available to help out if we needed. In those early stages the nurses were teaching us a lot. They were also managing and noticing how he reacted to things and what his preferences were. They were reassuring and very quick to help. That first night, when he started being sick, I didn't even need to buzz the nurse because she was standing outside and she could hear it, so she came in straight away and noted that the doctors had reduced one of his antisickness medications, so she arranged for that to be increased.

They would come in and check him over and they learned his little routines, such as he liked to have his temperature taken on a particular side. He was the driving force. They didn't force anything on him, and they would always look to us for reassurance before they did anything. [redacted] was the leader of his own care, which was lovely to witness. They were very reassuring all the time and kept calm all the time, and the ward was a fun place to go. He was always happy to go in and see them all. They were a wee family. It was a positive place and the staff made it as easy on the kids as they could. The nurses were very strict on the timing of [redacted]'s observations

and the timing of his medications. They were almost ahead of the game in knowing when his next dose of medication was needed. In one particular instance he was spiking a temperature. When a child spikes a temperature, they rely on paracetamol as ibuprofen is not a great drug to use along with chemo. On this occasion the paracetamol had taken the edge off, but he was still above 38 degrees, and he was due paracetamol at, for example, 7 o'clock. The nurse was standing ready with it at three minutes to seven. We didn't need to chase them for medication or anything ".

Q Thank you Mrs Gough. You can put that to one side now. You've given us quite a lot of descriptive evidence about the facilities and about the care on Ward 2A and what I want to do now -- I'm still focusing on events in August 2018 -- just to try and develop the chronology a wee bit from there. You've already told us about the diagnosis on 30th July of a Wilms tumour, and what frankly, sounds like a sort of rollercoaster experience, even then. Would that be fair?

A Definitely.

Q And the first thing was to confirm that it hadn't spread, and then next it is the treatment has to start, and

I think you've said, and Mr Gough said yesterday, the plan was: hit it hard with chemotherapy, remove the kidney, biopsy the tumour, and take it from there?

A Yes.

Q And so the first stage, then, you've already alluded to surgery, the first stage would be to have that surgery, which was to have something called a, "Hickman Line", fitted?

A Yes.

Q Mr Gough gave evidence some about that yesterday and for those who want to cross-check Mrs Gough's reference at paragraphs 42 and 52, she does the same. I wonder -- by all means if you want to have a look at what you've said, do so, but I wonder if you just want to give us a description of what you recall a Hickman Line comprising.

A Well, it is a general surgery -- a general anaesthetic, sorry -- and the surgeon makes two insignificances, one here in the neck, and one round about here.

Q You are pointing to the chest area?

A Yes. Your pec muscle if you like, not that there's much there, but anyway. They make an incision there and they put a line in to the central vein, and it is a long white tube and at the end of it, then, there are two access points. So that tube, the incision up here is to make sure that they have got it in right or to help them guide it in, so there was nothing up there other than a scar, and when the tube comes out, then they loop it in a wee O shape, and then they stick it on, and that was to make sure at that stage that it didn't get pulled out, so a large, clear dressing was stuck on top of it, and from that, then, two lines, and on the end of the lines, then, are two green caps, and those green caps are antiviral, antibacterial caps, and we were told, "Don't interfere with those caps, don't touch them. If they fall off come straight in", and I was a bit tentative of that whole thing because it was a direct line into him.

Q So you were given quite a bit of advice about --

A Care of it.

Q -- keeping the line clean and about the importance of that.

A Yes.

Q And I think [redacted]'s chemotherapy then began, and I think he was discharged on 8th August. I think in your statement you indicate that you were given quite a bit of advice about what would lie ahead, and were you given protocols as to particular things that you should do?

A Yes. He had chemo that first Thursday and over that weekend they were managing his reaction to the chemotherapy. He was quite ill, quite nauseous, lots of vomiting, and you saw the impact of the drug on him. He took to his bed, he really was not -- he was a shadow of his former self, to use a phrase.

Q So it started very soon after starting?

A Straight away. That Thursday night, actually the statement I just read out saying, "That first night", that was the first night of chemo, not the first night in the ward, so you've got the surgery on the Wednesday, chemo started on the Thursday, and on the Thursday night the vomiting started, and the nurses told us, you know, “The symptoms that he will get from chemotherapy are all manageable. Don't accept them. Tell us, so that we can help you manage them.” So he was on one type of antisickness medication and when he started being sick they gave him a different one as well so he ended up with two, and it's all about tweaking it to make sure it's the right level for him so that they could manage his symptoms to keep him as comfortable as possible, so they were teaching us all of that, knowing that we were then going to take him home and be managing that at home.

Q So just for us all to try and understand where you've reached by this stage, you are being discharged just over a week after you've discovered that [redacted]'s got cancer.

A Mm-hmm.

Q It sounds from what you are saying that quite a bit of information has been provided to you over that period.

A Quite a steep learning curve.

Q Yes. I mean, would it be fair to say that communication was a key part of the process in managing [redacted]'s illness on the part of the clinicians?

A Definitely. We really felt that we were part of his care team. We were part of the care team and we had to be brought up to speed, up to their level, so that we could be trusted with him at home. There was a two- or three-page A4 sheet and I really wish I had kept hold of it, that had -- it was a standard sheet, but it had [redacted]'s information handwritten onto it, and it was a tick box to make sure we knew and understood everything, and she went through it with us, almost an induction form, and, "Are you happy with the Hickman Line? Are you happy with what you do with the Hickman Line? Are you happy with giving him his medication? Do you understand his medication? Do you know what to do if he has a temperature spike?" And she almost tested us, "What do you do if he has a temperature spike? How do you manage this?"

Q When you say that she almost tested you, and when you indicated that there was a box which you were to indicate whether you understood, was part of the process --

A Definitely.

Q -- that they wished to satisfy themselves that you did understand what was involved?

A I think both parts, to make sure that we were happy to take him home. We were anxious, we were really anxious about taking him home and taking on that level of care.

Q And did you feel you were able to deal with, process, understand and respond to detailed and what was probably quite complex information?

A Yes. We felt supported.

Q Do you remember being given, for example, particular advice around temperature and what to look out for and how to respond?

A Yes.

Q Do you want to tell us a bit about that?

A Yes. The magic number is 38. As soon as he hits 38 degrees, that is classed as a fever, and we had to high tail it to the hospital. If you can't get here under your own steam within an hour, phone an ambulance and tell them that you are an oncology patient and that you need an ambulance to the hospital straight away because we had to treat it as a line infection, and we were warned that if it was a line infection that it could go bad very quickly, and just -- it was a "Just get here. Phone us straight away, give him paracetamol and bring him in". Now, if we got to the hospital and his temperature was only 36.5 from being out in the cool air, that didn't matter. If we had got a reading of 38, that was enough to start the process of antibiotics and a culture taken to check for an infection.

Q And so what would happen? I mean, sorry, maybe a question before that, I think it's obvious from your statement that [redacted] did regularly experience what are described as temperature "spikes". Again, it's no doubt self-evident but what is a “temperature spike"?

A When your temperature goes above 38.

Q Yes, and what was the protocol then when that happened? Straight to hospital?

A First thing is phone in, because depending on what time of day it is, would dictate where you went, so if it was during office hours of day care, which was 8 until 6 during the week, Monday to Friday, 8 until 6, you could phone in to day care and say, "[redacted]'s got a temperature, right, okay, bring him in", and that would be it. They would know we were coming. and they would be set up and ready, so when we arrived, he would be taken straight in and given antibiotics straight away. He would be a high priority. He would bump anybody else that was sitting in the waiting room.

Q Why would he be given antibiotics?

A In case it was a line infection. They would start treating it as a line infection straight away, as a prophylactic.

Q So essentially, am I right in understanding, that protocol was, your point of view, assume this could be a line infection?

A Yes.

Q I.e., assume the worst?

A Yes.

Q And from their point of view too, assume this could be a line infection, hit it with antibiotics but carry out some investigations as well? Is that right?

A Yes. They would take a culture. They would take a culture, and that would be sent away to the lab, and give it 48 hours, and if nothing had grown in the lab after 48 hours then you were free to go home.

Q And was readmission for a 48-hour period a regular feature of [redacted]'s treatment?

A That became our standard. We were bumping in and out of there. A Wilms tumour is a rare one, and we were the only people on the ward at that time with a Wilms tumour. Another wee child had just finished treatment, and as we finished another wee child just started treatment, and the next family were told, "You will be in and out of here constantly", because we had been in and out of there constantly, and to clarify, we were part of a medical trial.

All of the children getting cancer treatment are part of a medical trial because none of this stuff is tried and tested, if you like. The process of it is that they're all treated like guinea pigs. They're tweaking the treatments constantly to try and get the best of them, so they were warned, "You are going to be in and out of here all the time" and they were only in once on a spike, whereas that was the way [redacted] reacted to the chemotherapy.

Q Yes. Another thing I think you indicate that you were given advice about when you first left Ward 2A with [redacted] was infection control within the home --

A Yes.

Q -- within your own home in particular. What was the advice around that?

A I already mentioned that we upped our game to the level of the gold standard on the ward, so the night before [redacted] came home, I went home and left Cameron to do the night shift, specifically to clean our house from top to bottom and make sure that it was gold standard ready for him to come home. I did mention that Cameron had been fitting a bathroom in that first week. He had done all the grunt work and I had to go home and do all the cleanup. The nurses did say, "Don't be coming out with hunners and hunners of bleach because the bugs that are in your home are your bugs and his immune system should be able to cope with that". I didn't really listen to that. We believed everything at home. We had antibacterial wipes agogo. In fact, Cameron, I'm sure he talked about his grab bag and the grab bag, the first thing on the top of it was the antibacterial wipes and we just wiped everything wherever we went. [redacted] wasn't allowed to touch anything until I had wiped it down.

Q The next thing I was going to ask you about, and I think it's maybe obvious from what you've said, was how [redacted] coped with his chemotherapy. It sounds like from the start it was pretty sore on him. Would that be fair?

A Yep. Gruelling. Gruelling. That first four weeks, because of all of the additional temperature spikes, they suspected -- the phrase they used was, "Die off" -- so they suspected that the chemotherapy was killing the tumour, and so all of the toxins that were in the tumour were getting dumped into his system as well, and so they thought maybe that's why he kept spiking -- because of that, because of the toxins that were going into his system.

He was tired, he had no stamina. He was sleeping a lot more. He couldn't walk any great distance without having to sit down and rest. He was emotional, much more emotional which, again, was the tiredness. He was a bit battered and bruised from that first day of getting the cannulas. Once the Hickman Line was in place, the need for cannulas was gone, so that was good, and he was looking forward to that, because he didn't like the things in his arms.

Q So he had had cannulas prior to that and that's not something that he enjoyed?

A No. Definitely not.

Q And you've maybe already indicated the answer to this, how was [redacted] within himself over this period?

A Amazing, I think. He kept positive. He didn't know the gravity of it. We played it down to him. "You've just got a wee bug [redacted]", and we explained what cancer was and how the cells in your kidney have done something funny, so we just have to have some medicine and then we are going to take it away, we are going to take the cancer away and you are going to be all better and that will be fine". He was still a happy kid because we worked hard to keep him happy.

Q And just coming up towards the end of August 2018, I'm going to ask you about one particular incident, and you describe how, on 23rd August, [redacted] went to Ward 2B, the usual way, for his outpatient chemotherapy, and that he suffered a temperature spike on that occasion.

Now, for anyone wanting to follow

this in Mrs Gough's statement it is paragraph 65 where this begins. Mrs Gough, by all means, have a look at it if you wish.

A Yes.

Q Do you remember the event?

A Yes.

Q Can you describe to us what happened?

A What happened? He had a spike that morning and we, naively, we didn't follow the protocol. We didn't give him paracetamol as we left the house, and when we got in then he kept deteriorating and it was a very busy day care, and we were put into one of the little clinic rooms and they were waiting to -- they had taken cultures and they were waiting to take us over to day care, and so while we were waiting in that room his temperature continued to rise, and he started shaking, which we then learned was called, "Rigour".

We had seen that before in [redacted] as a child, he has had temperatures as a child and we had seen that before so we knew, "Oh, he's not doing great", but we didn't raise the alarm, so that was a learning curve for us, and when the nurses came to transfer us across the corridor to the inpatient unit, she -- "Oh I'm sorry, oh, you should have come and got me, oh right, quick", and she got help quickly and he was given -- there was suddenly five doctors in the room, and they were monitoring him closely for the next eight, ten hours to make sure that didn't happen again, because rigour is one of the flags for a line infection. So that kind of gave us a spook, "Oh, we need to pay attention to that more. Don't make that mistake again".

Q Okay, and do we understand from your statement that [redacted] was put into a vac room on this occasion?

A Yes.

Q And you've described how he was monitored very closely, and I think eventually the cultures came back negative. Is that right?

A Negative. Yes.

Q Was [redacted] on antibiotics at this point?

A Yes. He had a reaction to the antibiotic that they had been giving him, and his cheeks flushed. That was it. Just a wee rosy cheek, "You are looking rosy [redacted], are you a bit hot? Let's check you", and second time that they gave him it, they observed, "Right, his cheeks flushed again, right, he's not allowed that antibiotic anymore because that is a reaction and we are not willing to risk", so he was not allowed that particular antibiotic, so that got added to my diary of, "Don't give him that one".

Q Was from any particular advantage to [redacted] in his being put into a vac room on this occasion?

A It was a cooler room. The air conditioning worked and that's the first time we had experienced that, because the last two visits that we had had, we had been an inpatient in Room 10 and I think it's just coincidence, it just happened to be the empty room when we came back, and the air conditioner didn't work in Room 10. It was 25 degrees. You think it's warm in here? It was roasting. It was awful. One of the ways of coping with it was the little bottles of water were put into the freezer so that you could take a bottle of ice to your room so that you could always have a cool drink to have. I took that on the third, fourth night. I had a bottle of water sitting on the nightstand, and as it sat on the nightstand condensation built up on it and puddled on to the table beside it, and fried my phone, so that was an emergency call to my big brother saying, "Help, I need a phone". As soon as Cameron arrived that morning, “Phone Tony, I need a phone". My brother had to go and buy me a new phone so that I could contact the outside world.

Q Was there no mechanism for controlling the temperature in the other room?

A There was a little white box on the wall where you could push the button to -- the negative button to make it all cooler but it didn't do anything. It lit up when you pushed it, but it didn't make any difference.

Q Did you complain about that or tell anyone about that?

A We asked the nurses, "What's with the heat? Why is it so warm? Can we make it cooler in here?" because it was July and August, it was hot outside, and “No, it doesn’t work”. That was the "No, the air conditioner doesn't work".

Q Did you get any impression as to whether this was something that was isolated to Room 10 or whether there was other rooms that might be affected?

A I think it was across-the-board. I got the impression that it was across-the-board.

Q In your statement at paragraph 159 you indicate effectively the nurses just accepted that that was the situation?

A Yes, and it was a message to my big brother -- as I said, I'm one of seven, so keep referencing

different brothers, sorry -- one of my elder brothers is a nurse in England, and so he was the medical input that I would get, text messages back and forth to him, and when the message went out that, "Colette's phone is fried, she will be back on line as soon as Tony sorts her out.” When I told the story to them, saying, "Oh yes, it was just a bottle of ice melting on the night stand", and they were like, "What do you mean? Where's the air con? Why is the air con not working?" And it is only when somebody outside of the circle says, "Why is it not working?" that you think, "Why is it not working? This is a new hospital. It's only been open a year-and-a-half.”

Q Any views on how suitable it is to deal with children who are running a temperature in rooms where you can't control temperature?

A It's awful. The first thing you do when a child is running a temperature is cool the room. The recommendation now isn't to put cold compresses on them. We were told that when [redacted] was a baby and would have a temperature, that you shouldn't do the cold compresses, you shouldn’t do that, you should just cool the room, and as a baby when he had a temperature, we would sleep with the windows open so that he would be cooled to the point of wearing a hat yourself so that you wouldn't be cooled, because he has always run hot. When he would have a temperature, it wouldn't be unusual for him to be over 40 degrees, and so trying to bring his temperature down was terrible.

We had cold packs. They would have these, like, what the children get at school when they bump their head, and it is a chemical reaction, so you snap the wee thing inside it and shake it and it is a wee chemical reaction inside the bag that would be cold. It's not ice, it's just cold. He would have cold packs on the back of his neck. I would be doing cold clothes over his eyes to try and cool him down. I bought cool cotton pillowcases that were being sold as ones that would keep you cool to put on the pillows because the hospital pillowcases were all -- what's the word I'm looking for -- flannelette-feeling, so they would be cosier, if you like. Anything to try and cool him down. We had shorts and T-shirt jammies, he wouldn't have covers on his bed. If I was lying -- definitely those early stages, when he was staying in, I was sleeping beside him on the bed because he didn't want to be himself on the bed. I would be lying beside him, but I couldn't cuddle into

him because my heat would make him hotter.

It was very difficult to manage, and you couldn't leave the door open because of the noise in the corridor, or because of the light in the corridor at night, so trying to keep the room cool at night was terrible. Absolutely terrible. He had a headache constantly from dehydration. I suffer from migraines when I get dehydrated, and I had a constant headache that fortnight.

Q You've already described to us that therapy was pretty grueling in itself. Are you able to say whether this issue with the temperature in any way exacerbated the symptoms that [redacted] was experiencing?

A Definitely. Definitely. We couldn't get him cooled, and if I had a headache, what did he have?

Q Now, there's two other things that I want to ask you about and we will complete, I hope, your evidence in relation to August 2018 before the mid-morning break. The first of those things is something that you refer to in your statement at a number of points which you call, “The Schiehallion umbrella". I'm going to go on later and ask you a bit about whether the Schiehallion umbrella was something that was available to you elsewhere in the hospital, but we need to start by first of all understanding what it actually is. Are you able to describe to us what, for you, the Schiehallion umbrella comprised?

A The level of care, the attentive nurses, the number of nurses and the availability of the nursing staff, the level of cleanliness and the level of -- the different infrastructure that was in place to support the children while they were going through their treatment. The support for the families that was there in Schiehallion, so all of the things that we've alluded to this morning: the playroom, the kitchen, breakout space, the particular -- the attention to the particular details of the level of care required for a immunosuppressed child. It doesn't exist in other wards in the hospital.

Q So Mr Gough gave some evidence on this yesterday, and I will just reprise what he said, I think it is implicit in everything you've just said. One aspect is the experience, the expertise, the paediatric oncology and all the demands around that. Is that fair?

A Definitely.

Q One of those demands must be the recognition that some aspects of this, and you've explained how [redacted] maybe didn't really know precisely what the bigger picture was, but aspects of cancer care and cancer treatment for children must be nothing less than terrifying?

A It's awful, and I don't know if anyone else in the room is parents, but taking a three-year-old for their booster jabs, everyone has experienced that, where they don't want to get the jag off the nurse, and you brace them for it, and you hold them in tight, and you nod to the ladies and they jab away and the wee one screams and squeals and you give them a wee toy or a wee sweetie to get them through it and then it's all forgotten because it's just that one instance.

In cancer care that's once a week or once a day for however long the treatment lasts and the approach that the Schiehallion team had to every procedure and every interaction with [redacted] was about the long game, and that didn't transfer when we went to other wards in the hospital. That was part of the umbrella, that they had an awareness, that this wasn't just about getting through today and getting through this particular procedure, it was about getting through the next nine/ten months of procedures, and that’s the experience that the Schiehallion team bring, the expertise that they have.

Q I mean, there's a variety of challenges, it's obvious, you've just touched on another of them, the carrying out, regularly, invasive procedures on children, the provision of treatment that, of itself, was making children unwell. All of these things, I imagine, require careful management on the part of staff?

A Yes, and the staff need to know how to manage us parents as well, because we have to be part of the treatment plan. I have to be comfortable with what you are doing to my son because I'm quite resilient that way, and he had his tonsils out when he was three years old, and when he was getting put under with the gas and air he kicked off a bit, and that's a reaction to the gas and air, and the doctor looked to me to say, "Shall we continue", and my response was, "Yeah, hurry up", because he's wriggling now and he's quite strong, but some parents would have said, "No, no, no, stop, my poor wee baby, my baby". Cameron and I were both very much on board and with the team saying, "This procedure has to happen, how can we all make it happen as less painfully as possible".

Q And do I take from what you've said that one of the reasons that that relationship arose was down to the way in which the Schiehallion staff communicated with you?

A Definitely. We were part of the care team. They gave us as much information as they could.

Q And so would you say that part of the Schiehallion umbrella, then, would be clear, sensitive but also candid communication?

A Definitely.

Q And with that umbrella over you, perhaps you feel a bit safer as regards the --

A It is the confidence. It is understanding, not just that they have to do a procedure, but why, and what the background behind it is. "We are doing this because this is the long-term gain here". Dr Ronghe was fabulous at guaging how much information to give us and when to give us it, because that -- especially that first fortnight in August, was overwhelming.

I have already said the learning curve that we had, because first of all, we were learning about oncology and how to care for [redacted] in that environment, how to help the care for [redacted] in that environment, and also taking him home, but also we were learning the intricacies of a Wilms tumour and what the long-term impact of that would be on his life.

We were warned, "Don't Google". Of course, we Googled. But instead, Dr Ronghe said, “Right, well, if you want any questions, write down any questions that you may have, even if you think of them at any point and we will answer them the next time we see you”, so, again, the diary and the notepad, any questions got written down, and they gave us clear and proper answers to any questions that we asked. He also, then, gave us direction to actual medical research papers, "Don’t Google it, look, read this", and gave us the links to the research papers on Wilms tumours that -- some of them he had partly published, they were part of his education and research to give us a background to help us understand, and some of the words.

I mean, I can't remember them now, it was quite a learning curve, but the intricacies of cellular structure and the impact that that would have, so we were learning the words that pathology were then going to be using to then stage [redacted]'s care, they gave us as much information as we asked for.

Q Do you think that it was something of a two-way street in a sense, that he has tried to assess what it was you needed to know and what you needed to know?

A Yes, and what my capability of understanding it was. I'm not a biologist, I'm not a microbiologist. Some of the words and phrases that were in those papers were harping back to Cameron's university days. He did biology and zoology at university, so he was saying, "Oh, that's familiar, yes, that's kind of familiar", so he was helping explain it to me. I'm a drama teacher. I don't know about that stuff. I don't need to know about that stuff, but I learned about it, so that I could understand it, and it is a very American thing to say, I became a, "Momcologist", but you do because you have to learn it and understand it, and we became the experts in [redacted]'s cancer and [redacted]'s care.

Q Okay. One last thing I want to ask you about, and we will then move on to your experiences in other wards. We've already touched on this, and I think you've already provided an answer to it to some extent. Was there an indication over this period that there might be some concern about the safety of the water that was being used in the Schiehallion Unit?

A Not from any member of staff. There were signs on the sinks saying, "Not drinking water" and "Don't pour anything down the drain".

When we were first admitted, there were no water filters on any of the taps, but by our second or our third admission at some point in that first month the tap filters appeared, and I questioned, "Oh, what are they?" because they get in your way when you are washing your face at the sink. They're quite cumbersome. If you imagine, that's the end of the tap, the thing is that size, they're big discs, a big doughnut, so it really does impinge on your space around about the sink area. "Oh, what's this for? Oh, there's been an issue with water and it's just to keep everybody safe", the caveat for everything was, "Just in case." It was just in case, "There's not an issue, it's just in case", and a few other parents kind of, "Oh yes, there's been an issue with the water in the past", but nothing official. Nothing in writing, nothing official.

Q Okay. If you will forgive me, Mrs Gough, I wonder if we can look, again, at your statement, so if you could go again, please, Ms Ward, to Bundle 3. If you take us to page 142, I think it is, I want to go to paragraphs 150, 152, so I beg your pardon, Ms Ward, it's --

A Page 141?

Q Thank you. I suspect

we've all read paragraph 150 now so if we could now just go to page 142?

A Do you want me to read this out again?

Q Please.

A "We were told to use bottled water for drinking. When we first went on to the ward there weren't any filters on the taps, but they appeared at some point in the first month. We were told by the staff that there had been issues with the water at the start of the summer. It was on the news apparently, but we didn't pay attention to it, and we weren't aware of it. When we did mention it, other parents were told that there had been an issue and that's why the filters were on the taps and why we were using bottled water. It was very much played down by the staff. Whenever you asked about it, they said to use bottled water and the filters on the taps -- and filters are on the taps and not to touch them or interfere with them and that was it".

Q Can I just pause you there, please? "It was very much played down by the staff"?

A Yes.

Q What do you mean by that?

A It was brushed -- not brushed aside, but we were -- “Well, what's that?", "Oh, it's nothing, don't worry about it. Don't worry about it. It's fine."

Q And, you know, where was that advice emanating from? You know, which -- was it from nurses? Doctors, or --

A Nurses, auxiliaries, in any room, whatever members of staff came into our room, really.

Q Could I take you back to 152? Could you just read this out for completeness, please?

A Yes: "We were allowed to use the water for washing although there was a sign in the bathroom telling you to run the water for three minutes before you use it and the shower every day. We were also told by staff to run the water before we used it. I assumed that was for legionnaires. There was also a sign saying for hand washing only at the sink in the bed area, so we did tooth brushing and stuff in the bathroom. We used the water in the bathroom to brush our teeth and nobody told us we shouldn't".

Q Thank you very much. We can put that to one side. One further aspect about water in August 2018 that you describe in your statement was an incident involving use of a shower. Can you tell us a bit about that?

A We had cut [redacted]'s hair. He still had a wee boy hairdo, long and floppy, and one of the ways of managing the high temperatures and the heat in the hospital was, "Let's get that haircut, let's get all that weight off his head and that will help cool him down", but so as not to scare him, he had never had buzz cut, to use a phrase, using clippers, it had always been a barbers using scissors, so to let him have that done without it being scary, and from speaking to the nurses when we were talking about -- well, he has been on chemo now for two weeks, at what point now would the hair start falling out, what's the best way to manage that so as not to scare him, and their suggestion was, cut the hair short so he will then not notice it the same. He will not notice the wee hairs the same as you'll notice the longer hair.

So, to make it fun, as was our way, he got to cut daddy's hair first, so he loved that, that he got to cut daddy's hair with the clippers. We did it in the shower room, and then I was, you know, me being me, scooping up all the hair, putting it all in a bag ready to put in the bin, and then I left them to shower because they were both covered in wee bits of hair, and I was sitting in the bedroom while they were in the bathroom, and when I was sitting there the water started coming out. I say, "Started", I didn't notice it until it was already out and flooding the entire bedroom, so it came out of the bathroom door and flooded across the floor and out into the corridor.

Q Am I right in understanding you were in a vac room at this point?

A Yes. We were in Room 24, I think.

Q So this came out from the bathroom into the immediate bedroom into the lobby --

A And all the way out through the door because the angle of the floor meant that it was keeping running.

Q And then out into the corridor?

A I caught it at the corridor door with the towels that were sitting there and then ran to get more.

Q Yeah, and so what did you do?

A Mopped it up. I was mortified, "Cameron, you've blocked the shower". I was blaming him, and then when I went in and saw, no, the shower's not blocked, it's just water running everywhere.

Q Was your assumption

that you were going to go in and find a whole lot of hair?

A Yes, I was expecting to find the drain covered because he's a man. He wouldn't notice things like that. Sorry Cameron, but it wasn't his fault. The hair was all lifted.

Q Yes. It had just flooded.

A It had just flooded and gone everyone and when we mentioned it to the staff then, because obviously they saw me running, and -- “What's wrong?”, “The shower's flooded, the water is everywhere”, “Oh, that's happened before, right, I will report it”, and it was an eye roll.

Q Did anybody come in and clean the room after that happened?

A No.

Q I mean, are we right in understanding that the toilet area, the bathroom area, had been completely inundated with water?

A Yes.

Q And that that then flowed into the bedroom?

A Yes.

Q Without putting too fine a point on it, that bathroom is not going to be the cleanest area that you've ever been in?

A Well, it was clean when we arrived, we trust that, but we had been using it in our stay. It was a used bathroom. It gets cleaned every day; the cleaners would be coming in to clean it every day. I can't honestly tell you if they had been in before or if they came in after. I don't remember, but yes, it was a used bathroom.

Q Yes, and water that had been in the vicinity of the toilet area --

A Yes, it flowed all over the floor, and then out past the toilet, out that corner, so as you open the bathroom door, the toilet sits here behind the -- it is a double door, but one door is much bigger, if you can imagine, so there's a smaller door that will open, so that it is a completely open area.

Q What you are saying, there was no disinfecting of the room or anything like that after that?

A No. I don't think so. Not that I'm aware of. Not that I can remember.

Q And was your impression that this was something that had happened before? Did that issue, or the signs of a possible issue with the water supply, did that, at this point, give you any cause for concern about the safety of the hospital?

A No. I didn't think it wasn't safe at that point. I thought it was ridiculous, the building wasn't up to standard, and that this was supposedly

our flagship hospital, that it was supposedly the best place in Scotland to come for care, and laughing about it with my dad and saying, “Would you believe this, the shower flooded.” My dad is a retired carpenter and has worked on many a building site, and his reaction was, "That's ridiculous, where was the clerk of works? Why is that?" You know, very old school, because I was, to be honest, laughing about it, saying, "This is ridiculous". It's just yet another thing that doesn't work, and that was the response of the staff as well, that, “Oh, right, another thing broken, another thing not working right.” Don't get me wrong, we were grateful to be in that room because the air conditioning worked, so, "Don't move us, no, no, we will stay here with the dodgy shower, that's fine, we will just put barriers of towels up every time we have a shower".

Q Is that what you did?

A Yes.

Q Thank you, Mrs Gough. My Lord, I'm about to move on to a new chapter. I wonder if this would be a convenient moment.

THE CHAIR: Yes indeed. Now, I make it 11.35. If we break for 20 minutes that would have us back at 11.55.

(11.35 am)

(Short break)

(11.55 am)

THE CHAIR: Could we ask Mrs Gough to come in? Right. I think we are ready to restart. Mr Duncan?

MR DUNCAN: Thank you, my Lord. For those who are following Mrs Gough's evidence via her witness statement, we are moving to paragraph 71. Mrs Gough, I'm going to start to ask you some questions now about treatment that [redacted] received in September 2018. I think we understand from your evidence that [redacted] was admitted to Ward 3B in The Children's Hospital on 3rd September. That was to have his kidney removed, and then to have the tumour biopsied. Is that right?

A Yes.

Q Just to recap, [redacted] is still seven years old at this point, he has been through four weeks of chemotherapy, and he is about to go through a really major operation. Is that fair?

A Yes.

Q How did you feel about that?

A Apprehensive, although the anxiety level had been up there from that first day, if you like. He ended up getting five rounds of chemo was the scheduling of the surgery was slightly delayed, and that was due to there not being a space on the PICU available.

Q Just pausing you there, the PICU is what?

A The Paediatric Intensive Care Unit so they wouldn't schedule a major surgery like this without having space available in the PICU because the protocol is that they have the surgery and then they go straight to the Intensive Care Unit after that, because they will need intensive care at that point.

Q Yes, and [redacted] at this point is immunocompromised?

A Yes. He was what they class as neutropenic, so before he would get his chemotherapy each week, they would do a thumb prick in Clinic 3. We would do that on the way into the building and the thumb prick would give count of his red blood cells, his white blood cells, his neutrophils and his platelets, and for those that don't speak chemo, the platelets is the bit that clots the blood, white blood cells is the bit that kills germs, red blood cells carry the oxygen, and the neutrophils is the immune system, and how well the immune system is going to work.

To be called, "neutropenic", your neutrophils have to have dropped below 1, and [redacted] had dropped below 1 for the first time, and that's when he was at his weakest point because at that point he had no immune system to fight anything, so that was when a common cold would have been disastrous.

Q So at the point that he is going in for surgery he is at his lowest point. Is that right?

A Yes.

Q Do you recall, I think you indicate something to this effect in your witness statement, do you recall at some point being given some sort of warning from the Schiehallion nurses about the extent to which the care that you had come to rely upon would be available on other wards, including the surgical ward?

A Yes. When we were in Schiehallion that first visit, we got a tour of day care and where we would be going, and they were very careful to give us as much guidance as they could, and so before we were going to the surgical ward we were asking, right, well, what's that like? What do we need? And they were -- we were told that surgical unit -- "Oh, it's nice, it's not like here though. It's not as nice. It's not as family as here. They don't have the same -- like you've not got a kitchen or anything, and you've not got access to the same things that you've got here. There's not as many nurses."

We had heard a couple of horror stories from other parents who had been put into this ward saying that obs weren't being done on time, that they had been telephoning down to Schiehallion saying, "Nobody is coming, when we are pushing the buzzer, nobody is coming", so we were a bit apprehensive about going into a different ward and yet another space, yet another unknown.

Q When you arrived with [redacted] to Ward 3B, am I right in understanding that [redacted]'s room wasn't, at that point, ready for him?

A No.

Q And you went to the playroom? Is that right?

A We were just -- "Well, if you just go and wait in the playroom", while we are waiting.

Q And what was that like?

A Messy. Not clean. No play worker, no members of staff in it. Children in there unsupervised. Children with snotty noses in there unsupervised, which really was my issue -- not that the children weren't supervised, it was the fact that that child has got a snotty nose -- we are not going anywhere near that child.

Q To be clear, these are not immunocompromised children?

A No. The surgical ward has children from all areas.

Q And you were eventually, I think, directed to the bedroom that [redacted] would be staying in. Did you have any issue with that?

A Not at first. We went in and we had a visit from the ENT department who came to consult for [redacted] because they had noticed a weakness in his voice which can be another side effect of chemotherapy so they came to check his throat and make sure that everything was okay, and that kind of distracted us for a bit, and it wasn't until we were putting him into bed, trying to get him settled for bed -- It was a bit flappy, actually, that evening because the ENT guys came in, we were late getting into our room, the ENT guys came in with our big trolley to look down his throat with the camera, then when they went away dinner was getting served, and of course because he hadn't been there during the day his dinner was -- whatever was left on the trolley. He hadn't ordered a meal, so they was scrabbling together to try and give him a meal, and bearing in mind this is the last food he is going to eat before surgery because he had to fast from

midnight. So, we were trying to get him to eat quickly because it was getting cold so that we could then get him settled to bed. He was the last person to be given dinner, so it was late. Everything was bumped on later.

When we put him into bed we lifted the side guards of the bed and they were covered in something. Something brown. I don't know what it was. My immediate instinct was right, well, let's just wipe it and we will put him into bed because I was thinking, “Get him settled to sleep as he needs to sleep tonight so that he is strong for tomorrow". Cameron said, "No it's not clean. Tell the nurse".

We hadn't been admitted yesterday to the ward, we hadn't seen -- other than the nurses saying, "Right, there's your room", we hadn't actually spoken to the nurses because they were busy caring for other children on the ward. The wee child that we had observed in the playroom was there on a long stay, and so was there on his own, and the nurses were putting him to bed and tucking him in, and making sure he was settled. He was in the room opposite us, so they were busy, and there was only two nurses for the whole stretch of corridor that we were on. I bear no ill feeling towards them. To be honest, my feeling at that point was God, that poor wee child that's not got their mummy or daddy with them. I don't know what the family situation was but that's really sad that there's not somebody with him, that it is a nurse that's having to put him to bed at night, not my place to comment, that's their own family structure, but it meant that we didn't have a nurse come and see us, so the first conversation we had with the nurse was, "Our bed's dirty", and they were mortified. Absolutely mortified.

Q And was it dirty or was it just that there was a stain left over from it having been washed?

A Oh no, it was brown liquid that had dried on it. It needed to be cleaned. It hadn't been washed.

Q Now, am I right in understanding that there was a vac room on this ward, but it wasn't a vac room that you were provided with? Is that right?

A No. The room we were in was just on the main corridor.

Q And I think you say, just maybe looking at matters more broadly, is it right that from about this time you became -- maybe you already were -- in the habit of essentially cleaning wherever you went in the hospital?

A That was the first instance of us not being in Schiehallion and so, right, we cleaned that room straight away, as soon as we noticed that on the bed, right, get the wipes out and we started cleaning everything. Everything got wiped down with the disinfectant wipes.

Q Thank you. Now, let's move on, then. I think [redacted]'s operation was on 4th September, and as you've already indicated, he was admitted to PICU after the operation. It was a lengthy operation, yes?

A About five, six hours.

Q Right, and I think we know from your evidence and Mr Gough's evidence yesterday that [redacted] spiked a temperature. Do I understand from each of you that hat wasn't a major concern at that point, and indeed one possibility was that it was just a reaction to the anaesthetic?

A Yes.

Q I think Mr Gough yesterday recalled that it might have -- there might have been some suspicion of a line infection at that point, but --

A Well, any temperature spike is treated as such.

Q Yes. Moving on, then, to the following day, 5th September, [redacted] guess back to Ward 3B, and I suppose against the background of that raised temperature and that suspicion certain things have to happen, so they took line cultures? Is that how you would describe it?

A Mm-hmm.

Q And as you said, it used to be 48 hours for those to come back. I think in fact you described them on this occasion as having come back much more quickly.

A Yes.

Q And they came back and indicated that there was, indeed, an infection. Is that right?

A Yes.

Q And at that point I think you indicate, and for those reading the statement, it's paragraph 84, I think at that point, Mrs Gough, [redacted] received antibiotics via his Hickman Line at that point. Is that right?

A Yes.

Q Now, just pausing at this stage, [redacted] recovering from his operation and he has now got an infection, and presumably still running a temperature, would that be right?

A Mm-hmm.

Q How was [redacted] at this point?

A Small and fragile. Very small, very fragile. He was very weak. He was in a standard hospital bed which you can adjust to make comfortable, so his position was a raised back with slightly raised feet which meant he was sitting in a crouched position, and he would slowly slip down the bed, as you do, and to move him up the bed to keep him comfortable we would have to click his morphine driver. He had a patient morphine driver, so he got to click whenever he needed to a certain level, wait ten minutes, the pain nurse came in and talked us through this, clicked the clicker, wait ten minutes for it to get through his system and then we will pull him back up the bed, and that was traumatic for him. We weren't allowed to touch the bed; we weren't allowed to bump the bed because he was in so much pain. It was the most fragile I have ever seen him and that was very, very scary.

Q Now the following day doctors arrived and indicated that they needed to do some further investigations in relation to the line infection. I think you describe how they do something called a peripheral culture involving taking blood from the line and from the extremities, the hands and the feet. Are you able to describe to us what happened on this occasion?

A Yes. The nurse came in and took the sample from the line and then -- or the doctor, it was the first-year doctors came in, they took the sample from the line, and then they put the emla cream on his hands and that has to have time to work, so they left us and went out to do that. They went out to do something else.

A nurse came in and took his obs and took his temperature using an in-ear thermometer. Now, I haven't explained that to you, yet that [redacted] has different temperatures at different parts of his body. He's a freakazoid -- one ear runs hotter than the other, so if they don't take it in both ears then they don't get an accurate reading.

So, the nurse came in and took it from his cold ear and he was fine, and then he started feeling unwell. She was away, we were in the room ourselves with him, he started complaining of feeling nauseous. He was grunting, his breathing became laboured, the alarm beside him that was monitoring his heart rate, he had a little oxygen clip on which was monitoring heart rate and oxygen, the alarm started going off, and that was set at 120 beats per minute. When he went above that the alarm would sound. So, we pushed the buzzer and an auxiliary came, and we said, "[redacted]'s not feeling great, could we get some help", "I will go get someone", which is always their response, "I will go get someone", and no one came, and we pushed the buzzer again.

A couple of minutes later, by this point, [redacted] was vomiting. Now, vomiting for anyone is traumatic. Vomiting when you can't move or get yourself into a position to be able to vomit is even more traumatic, so we were trying to get him into a position so that he could be sick without hurting his stomach, because I think as Cameron said, he had an incision that ran all across his torso.

He was shaking. The alarm bell kept going, I silenced it, pushed the buzzer again, nobody came, and so Cameron said, "You need to go and get someone". Now forever I will kick myself for not just hitting the emergency buzzer. There are two buzzers in your room, there's a call button and there's an emergency buzzer and when you hit the emergency buzzer people come running because that's a crash call, and whenever anyone does hit it -- we've been there when it has been hit and nurses have gone, "I need to go", and they just run, and more often than not it is a small child hitting it by accident, thankfully. Had that quite a few times because the cots are right beside them, so the wains pull at them.

So, I went out and got to the front

desk and spoke to Helen, the green t-shirt lady who was the clerk, and at that point panic was bubbling in me -- and I know you can't imagine this -- but I couldn't really speak very well and I said, "He's going down fast", and the tears were starting because the panic was bubbling, "Can someone come".

When I went back to the room the alarm was beeping again, [redacted] was vomiting, and I went round and I held his hand and I tried to calm him down and I thought he was having a panic attack because they were coming to do needles. I thought that's why he was -- and I was saying, "Everything will be fine, look at me [redacted], just breathe, you need to breathe out darling", relax, because he was getting so tense, relax in the bed, the bed has got you safe, lean on the bed, let your body sit in the bed, try not to fight it, and he was vomiting.

The nurse that had just taken his temperature came back in and said, "I just took his temperature, and he was fine", and both of us shouted at the same moment, "You did the wrong ear". The poor girl, when she took his temperature, yes, he was up at 39, and then the first year doctors arrived and the comment back and forth and forgive me, this bit is all a bit -- because I wasn't really paying

attention to them, I was paying attention to [redacted] -- the comment back and forth was, "Have we started the antibiotics yet, no, because we need to get the peripheral first. Right. You need to get the peripheral. Okay. Hold him still and let's get the peripheral so that we can deal with this".

So, we were holding him down, or holding him still and supporting him as best we could while he was being sick, so that they could get the needle into his hands, and multiple attempts, they couldn't get the line in, multiple attempts they couldn't get the line in, and then they went to the foot, and I'm in [redacted]'s face saying, "Look at me, breathe, calm down, try and breathe for me".

The beeper is beeping, the staff nurse came in and upped the alarm level to 150 so that it wouldn't keep beeping, it started beeping again, kept pushing the button to silence it because it was beeping right in my ear, and then they were trying to get the blood out of the foot. We were holding him still as we could, and they didn't get it in the first attempt and they didn't get it on the second attempt, and, "Have you got it yet? No. Go get someone else then", and that's the first time I was rude to one of the doctors because every time we spoke to them we were so courteous and [redacted] as well. Every time somebody jagged him, he said, "Thank you", and it always got a laugh because you've just beaten him up and he said, "Thank you", because he is so well mannered. That was the first time that I was rude to one of the doctors, "Go get someone else then", because this is -- panic was bubbling for me.

I let go of [redacted]'s hand to let someone in to do something, take obs, let the nurse in to take obs and I lost my connection with him at that point and that's when panic took over for me because I wasn't holding his hand anymore and that was the moment that I was already seeing the nurse coming towards me saying, "I'm sorry, there was nothing more we could do". I was already there. He was already dying because the beeper was still beeping, and I had silenced it so many times, and I had to leave the room because I was having proper panic attack and I will never forgive myself for leaving him.

I feel incredibly guilty that I walked out when he needed me the most, and if that was the last moment, I wasn't holding his hand when I should have been.

Q Do you want to take a moment, Mrs Gough?

A The staff nurse was very kind, and she took me along to her office and I sat in her office for a few minutes and gathered myself, and just like that someone very kind said, "Take a drink of water", so I took a drink of water and I sat in her room and looking at the wall, the thing that was on the wall was the protocol for handing out the memory boxes to children, and what should be put in it for parents to take home when they lose their child.

So I sucked it up, I shook it off, and I went back to the room and when I went into the room it was a bit chaotic, there was lots of people that I didn't recognise, no one that had introduced themselves to us before, and Dr Hettle arrived who was a big American surgeon who was not our surgeon, but he was the one that was on call that weekend, and he was a superhero that day because when he walked into the room, everything calmed down, and I didn't get back to my spot beside [redacted].

I was standing beside Cameron on this side of the bed, and he went round and he sat on the end of the bed and the first thing he said was, "That line is off limits. Nobody touch it". He sat on the end of the bed, and he took [redacted] 's foot in his hand, and he said, "Hey [redacted], do you like dinosaurs", and [redacted], while vomiting, "Yes, I like dinosaurs", and he talked to him about dinosaurs while he took the blood, "Start the antibiotics, get a cannula in there".

He just took complete control of the room, and we really did feel that he had a clue of what he was dealing with because up until that point nobody seemed to know what to do to calm this situation down. It took about half an hour at that point for [redacted]'s heart rate to come back down again and for his temperature to come back down again, and when the room was finally quiet, Cameron and I just sat staring at each other saying, "What the heck was that? What was that?", but we didn't take too much time to think about it or dwell on it because our attitude for all of this was, "Right, what's next? What's next? What do we need to deal with next?"

Q And was what you needed to deal with next back to an almost identical event the very next day?

A Yes.

Q Now, let's move to the next day.

A Okay.

Q I think you now know that -- or I understand your evidence correctly, what [redacted] had experienced on 6th September was a septic shock. Is that --

A Not that morning. That word wasn't used until later on that day after we had seen it the second time, the septic shower was what they used.

Q Yes. Anyway, on the following day there was another instance, another issue like this. Am I right in understanding that by this point there was an understanding on the part of you and Mr Gough that there was a line infection?

A Yes.

Q And am I right in understanding from Mr Gough's evidence yesterday that there was a discussion between you and Mr Hettle, or Dr Hettle, as he may be, as to what should be done about that and there was to be, I think, antibiotic block is how it was described, put on to the line. Is that right?

A Yes. That came -- that direction came from microbiology, so Dr Ronghe and Dr Hettle came in that morning and said, "Right, microbiology want us to try and save the line and to do that we are going to put a finely measured concentrated block of antibiotic in the line to try and kill the bug".

Q Right. So, to take a step

back, let me move from Mr Hettle saying, "Nobody touch that line", everybody knows by now there's an infection in the line, the advice for the next day is, "The line might be salvageable"? Is that right?

A Yes.

Q And the way to salvage it would be to hit it with antibiotic. Is that right?

A Yes.

Q So Mr Gough explained yesterday that there had been a discussion about when that should happen, and it seemed to be a --

A Let's get on with it, yes. Let's do it quick.

Q -- let's not wait, but in fact it didn't happen immediately, and it was quite late on on Friday afternoon I think it was --

A Yes.

Q -- that it happened. Are you able to describe to us what happened on this occasion, Mrs Gough?

A The nurse came in and they took great pains to measure the exact amount of antibiotic going in each line. Now, the lines were not identically sized, so there was two syringes, one for each line, and they were very careful and double and triple checking their bits of paper and -- so it

is line A and it is getting exactly this amount of milliliters and they put it in, line B, right, okay, and off they went.

Exactly 40 minutes later [redacted] started -- his heart rate monitor started beeping at 120 again, and Cameron called it straight away. He said, "This is it happening again, get someone in here", so we pushed the buzzer and Jenny, who was the nurse that had been looking after us came in and said, "I was just in here, what are you doing?", the way they do, they always give them a row, "What have you been up to?" and trying to calm him, and the heart rate monitor was beeping, he was feeling nauseous again, it was all the exact same symptoms again, except this time we knew that it wasn't a panic attack so I didn't start any of that rubbish of, "Calm your breathing, take your time, focus on your balloon." God, I said that to him, "Do your balloon breathing, [redacted]", all the mindfulness breathing that we would do at school and at work and things, so Jenny came in straight away, and then it was one of the junior surgeons that came in because he was the doctor on duty at that moment, and, "When did he last have paracetamol? Right, okay, so he can't have paracetamol, he's not allowed it because it was within the last four hours, what can we do to get this temperature down?" The temperature was spiking, "Give him ibuprofen. Yeah, let’s try, give him ibuprofen", so they gave him ibuprofen orally and within about a minute he had vomited it back up again, and, meanwhile, this alarm is going again and again and I keep silencing it again and again and the panic isn't there for me the same, and I'm holding his hand and I'm not letting it go.

If you want to come and do obs on him work around me because I'm not moving, I'm not letting him go this time, I'm not making that mistake again, and I'm silencing the machine and silencing the machine to the point where I break the button on the machine, little plastic cover on it, and I have pushed it so many times that the plastic cover is damaged, and they're putting a bolus on which is where they flood the system with IV fluids for those that aren't medical -- I'm not medical but it is amazing the words that we learned when we were in that day -- and the doctor is standing, hmm, he's just standing back, hmm, this finger, hmm, and his eyes are getting wider and I'm thinking, "You don't know what you are doing here, you are not helping here", and the shock that [redacted] is in, and the fear, and he is being sick, and then two nurses appear from Schiehallion, Wendy and Jane. I have never been so pleased to see a face that I recognised, because, again, all of the people in the room are people that we don't know because it's ten to five on a Friday, and the doctors that are getting called in are the A&E consultant, because out of hours the doctor that's on call for the whole hospital is the A&E consultant, so it is the A&E consultant that comes in, having never met us before -- still don’t know her name because I didn't take it in when she said her name, and Wendy and Jane appear, and the first thing Wendy does is she runs into the room, or strides, with confidence, and takes somebody else's stethoscope in a very American medic moment, takes someone else's stethoscope and does obs on him and looks at the surgeon and says, "No more ibuprofen". Now, with hindsight, we know that children who are getting chemotherapy are not allowed ibuprofen because I talked about those four magic numbers, the platelets, the blood count. Ibuprofen stops your body from making platelets, that’s how it works. And if you’re already depleted in platelets, then you can’t have ibuprofen. They shouldn’t have been given ibuprofen. “Don’t give him ibuprofen again.” “Right, okay." And they stood back at the corner of the room, "Are you alright? Are you okay?", reassuring us. And then they stayed beside us, "How was it? Right, okay," and just monitoring him, seeing what he was doing. And then when the doctor came in from A&E, they stepped back, obviously giving seniority to the one that had just come in, but they didn't leave the room until everything had calmed down, and it took about 90 minutes for everything to calm down.

The A&E doctor stuck her head in – they were having a conversation out in the corridor – and she said, "Hi, I'm such-and-such, I'm from A&E and I'm a consultant, but I'm also on the infection control team so I'm interested in this. I see the bug, it's a poo bug." That was the word she used. "It's a poo bug." So, by that point, they knew the name of it. We were never told the name of it. "Yeah, it's a nasty one." And they were out in the corridor again and then Dr Hettel came in and said, "Right, he's going for surgery first thing tomorrow morning to get that line removed. We're not gonna try and save it anymore." And so, he had emergency surgery on the Saturday morning at 8 o'clock. And as he left to go for surgery, I said to Dr Hettel, "Don't be a

lift with him 40 minutes after you touch that line, because it seems to happen 40 minutes after you touch the line." And he took him for surgery, and when he came out, he came strolling into the ward and he said, "It was out after 10 minutes, but I stayed with him for 50 minutes and he's absolutely fine. He's okay. He'll be back up here" – 'because we stayed in his room, we weren't allowed to go – "He'll be back up in 10/15 minutes once he's out of recovery." And I broke all protocol and gave him a big hug and I said, "Thank you very much for listening to me." He didn't have to stay with him for 40 minutes, but he did because once the line was out the danger was gone.

Q Let's just look at one or two parts of that. You talked about, when speaking about the incident on the 7th of September, you made a reference to fear as the situation developed. Who were you were referring to there? Who was feeling fearful?

A [redacted], me, (inaudible), all of us.

Q Yes, but --

A Fear in the doctors' eyes. The room was not a calm place. It didn't feel controlled at any point. It didn't feel confident that we were gonna get a good outcome here, that this was okay. It wasn't calm. The room wasn't calm. The people weren't calm. The people were looking at each other-- The doctors and nurses were looking at each other and making eyes at each other over our heads constantly. "What's the obs now?" The student nurse, whose name I forget, they were in grey scrubs, she was taking [redacted]'s obs constantly. She just kept on reporting over what the heart rate was, what the temperature was, what the oxygen level was at. She just kept calling that over her shoulder.

Q So you're in a room where, effectively, you're going through a repeat of what you saw the day before, and even the doctors are looking scared.

A Yep.

Q How did you feel about that?

A I don't really care how they felt.

Q How did you feel about that?

A Not happy, not safe. When Dr Hettel came into the room, he walked straight to his junior surgeon and said, "You alright?", because he saw a face of fear. "You alright?" because it wasn't a controlled room. It wasn't a happy place to be. I

wasn't as panicked as I was the day before, definitely. I was more in control of my own feelings, but we were terrified. We were terrified that this was him going down again.

Q And so was [redacted], terrified?

A Uh-huh.

Q And did he know that that's where this could be headed? Do you think he was thinking that?

A I don't know. I've never asked him, and I don't want to ask him 'because I don't want to be planting that seed in his head.

Q No.

A Any discussion that we've had about this has only happened in the last weekend because he didn't know we were coming here until Sunday. We've kept him from it all. He's been through enough. And when we talked to him about it on Sunday, saying, "Do you remember when you weren't well after your surgery? Do you remember that?" And he said, "Oh, yeah, when there was like seven doctors in the room, and I didn't know who any of them were." That's his memory of it, and I'm so glad that he was on morphine and that he had drugs to dull it all. I hope that he's not traumatised by it the way that I've been, and if he is, then we'll work with him and we'll help him. We've been doing a lot of work with him post-event to give him the language that he would need to help deal with something like this. But I don't want to plant my emotions onto him. That's not fair.

Q I understand. Now, I want to move on a little in relation to these two events and to this question of the line infection. I'll ask you a bit about communication around this. You've already told us that there was a reference from the A&E clinician that this was a poo bug.

A Uh-huh.

Q I think we can see from your statement later you had a meeting with Dr Ronghe and, I think, Dr Inkster.

A Dr Inkster.

Q That'd be on the 17th of September 2018 --

A Yes.

Q -- and there was a discussion about these events then, is that right?

A Yes.

Q And what did they say?

A They apologised and told us that the infection that he had-- They gave us the name of it, that it was serratia marcescens, that it had come from the drains and that he was not an isolated case, but there were six other children-- he was one of six children, sorry, who had fallen ill around about the same time, and that there seems to be an issue with the building and the drains and the water, and because of that, the plan was to close the ward and to transfer the whole unit to somewhere else in the hospital. At that point, they didn't know where or when that would happen, but they were working with the estates to try and rectify the problem. But ultimately, that they were very sorry that this had happened.

Q So if we think back to the evidence earlier, your first contact with the Schiehallion unit in August 2018, and there were signs, (inaudible) signs, that might indicate there might be an issue with the water, is that right?

A Mm-hmm.

Q And now, on some six weeks on from that, [redacted]'s had two events that could have been disastrous --

A Yep.

Q -- and you're being told that that's to do with an issue arising from the water.

A Yep.

Q How did you feel about that?

A Quite angry. That's the

reason we’re here today because we-- Sorry, when I say “we”, I mean my husband and I. We really feel let down that we put our trust and our faith in the hospital. We couldn’t very well say to them, “Well, that’s fine then. We’ll take our son and go.” There’s nowhere else to take him. He’s getting chemo. This is the place you have to take them for the chemo. These are the experts. We need access to these experts. And I really did feel very sorry for Dr Ronghe that day because he had been very guarded about what he could say to us, and to be honest, I thought we were going in for him to tell us that the cancer was worse than we thought. That’s what I thought that meeting was about because he had been different in his-- Now, by no means did we have a friendship, but we had a relationship with him through ’s treatment, and it was different. “What’s wrong? Is he not telling us something?” And so, when the apology came and the realisation that it was actually because there was an issue with the supply, and when Dr Inkster then left the room, he said, “Do you understand? I didn’t know how much I was allowed to tell you.” Okay, because you need to protect yourself and your colleagues, I understand that. But the fact that he was very angry that children that he was caring for were not being better served, I got that impression from him. He never said it outright, but I got that impression from him, that he was not a happy bunny that day.

Q Yeah, thank you. Ms Ward, could we please have a look at Bundle 3 again and could we go to page 123, I think it is? And it’s paragraph 103 of Mrs Gough’s statement. Here, we see the evidence in your statement, Mrs Gough, about the meeting that you’ve just spoken about. On this occasion, I will read what you’ve written. What you say is:

> “Dr Ronghe asked for us to go in and see him on the 17th of September. We thought it was just for a check-up, to talk about how [redacted] was doing. Dr Ronghe came in and sat down and asked how [redacted] was doing. He was being very cagey, wasn’t chatting the way he normally would. We now know that that’s because he didn’t know what he was allowed to say with Dr Inkster being there. He

told us that after the meeting."

That's essentially what you've just told us, is that right?

A Yep.

Q And – we can put that to one side, thank you – are you indicating to us that you rather took from him that he was unsure about what he was allowed to say?

A Mm-hmm, definitely.

Q How did it appear to you that he felt about that fact?

A He wasn't happy. He was very angry that this had all happened. Now, I don't want to confuse because we've had multiple meetings with him since, and when we first started attending public meetings that culminated in this inquiry happening, we told him, we were open with him saying, "We've gone to these meetings. Is there anything you want us to say on your behalf?" Because we really feel that they had been let down. He's the expert in this field and he's doing his best in this field and the bit that's let them down is the drain? The building? We're dealing with cancer and the most measured of treatments and he's not getting to do his job properly. His hands are being tied. I got the impression he wasn't happy, but I can't speak for him.

Q Now, if we move on then just to perhaps complete your evidence in relation to September 2018. As we heard yesterday, the removal of the kidney disclosed at the chemotherapy had been more than successful, on one view, and it had rather destroyed the tumour, is that right?

A Yep.

Q And are we right in understanding that [redacted] was quite old, relatively, to have had this cancer in the first place?

A Yes, it usually manifests when children are around three years old.

Q And so was there then a bit of a doubt as to where the clinicians went next with [redacted]?

A Mm-hmm. The fact that he was at the top end of the age bracket meant there wasn't a lot of-- Like I said, he was part of a trial and so there wasn't a lot of literature to support the direction.

Q Yeah. But the decision was more chemotherapy?

A Yes.

Q By which stage, of course, his line had been removed, is that right?

A Yes.

Q So did I understand from your evidence that, for a spell at least, [redacted] had his chemotherapy by way of cannula?

A Yes.

Q And how did he react to that?

A Not well, really not well. The decision-- So they call it a “tumour meeting” – a wonderful name for a meeting on your diary, isn’t it, a “tumour meeting”? – and that happens every Wednesday. So, at that meeting, they have the radiography team, the oncology team and the pathology team, and they will talk about the tumours that they’re dealing with. So, [redacted]’s tumour was part of that discussion on the Wednesday before we were discharged from surgery, and they came back and reported, “Completely necrotic. There’s nothing to test, so we can’t stage it.” And that’s the magic word because the staging of it would’ve dictated the next line of treatment. Because they couldn’t stage it, Dr Ronghe said, “Go back and look again,” and we were told, “Take him home, let him heal, build up his strength and we’ll look at it again next week.”

So, they phoned us the following Wednesday after the next tumour meeting and they said, “The decision is that we’ll give him more chemotherapy for six months. So, at the first tumour meeting, the decision was either four week of treatment or six months of treatment, and if it’s only four weeks, then it’s not work doing another general anaesthetic. We’ll just do it via cannula. If it’s six months, we’ll get another anaesthetic and we’ll fit another access point.” So, by the time they decided that he was getting six months treatment and they had to schedule the surgery, his first chemo treatment after surgery was via cannula. And so, first of all, they have to make sure it’s in a deep vein because if it’s too close to the surface it can damage the skin, and second of all --

Q You say “it”.

A “It” – the chemo.

Q Yeah.

A The chemo can damage the skin, and also, they have to make sure that he’s completely still while they’re giving it so that they don’t move the needle within the vein. So, [redacted] is a robust nine/ten-year-old now. Then, he was a robust seven-year-old. He’s a strong boy and it took four of us to hold him down and hold him still, and by the end of it we were all sweating. You know, it was a workout because I had him round his torso, Cameron had him round his legs, one of the nurses had the arm pulled out, so we had to try and almost disengage his arm so that he didn't have any strength in it so that they could then pin the arm down and hold it still. And it was a "You're doing really well, [redacted]! You're doing really well, [redacted]! Just stay really still, really still, really still!" And at this point, he was not-- that's the only time he was saying, "I don't want it. Don't do it." He was screaming the place down. We couldn't cajole him; we couldn't rationalise it with him. Course we couldn't because look at what he's just been through. He has been a pin cushion and to get another needle-- and they have to watch every single drop going in to make sure that it disperses. So it's not just a wee quick-- It's a good minute and a half of staying very, very still. That's a long time for a seven-year-old when they don't wanna do it. It was awful. We were very glad that he was going for another surgery to get another access point fitted.

Q Yeah. So, I think-- Was it later in the month or a little later --

A The following week, yep. The following --

Q Yeah, he had-- And on this occasion, it was a port.

A A port, yes.

Q Yeah, and Mr Gough explained that to us yesterday. That's essentially accessed through the skin.

A Yes.

Q Yeah. Now, I think that took place on Ward 1A.

A 1A, yep.

Q And you speak about that in your statement at paragraph 112, for those following the statement.

A Mm-hmm.

Q And I think, to be fair, you're very complimentary about the care that you received. Am I right in understanding you describe it as the "gold star treatment"?

A Yes.

Q And what do you mean by that?

A 1A is a day surgery unit and, as a standard, you go in and you're all sitting in one big waiting area. And then, the children are taken one at a time for whatever their treatment is, and they're brought back to a big open bay. The children are going home that day, so there's no facilities for parents, there's no facilities to stay. It's just one big open area, and they're wheeled in, and they're wheeled out. It's constant on the move. But because [redacted] was immunosuppressed, he was given a private room and we were set right back in the corridor away from everyone else.

And when we arrived, again it was, "Just bear with us, your room's not quite cleaned yet. The staff are in cleaning it right now." So, that was all right. The room's clean. And the cleaner that was cleaning it is one of the nurses that also does Schiehallion, so I knew it was clean. Usually, when your child goes for surgery, you're just sent off to go and wander the grounds and walk off your anxiety, but because I had a private room, I could stay in there and wait for him there. So, when he came back from surgery, I was there waiting for him --

Q Thank you.

A -- which is unusual.

Q And you then go on to describe how [redacted] was transferred to Ward 6A in the adult hospital. And, again, I think you say actually that was also quite a positive experience. I think you describe everybody rushing around to --

A (Inaudible).

Q -- help.

A Poor staff. That happened to be the day that the decant took place.

Q The decant from the Schiehallion Unit into Ward 6A?

A Yes. So, when we arrived, they were up and down that corridor, constant running back and forth. Not walking, running back and forth. Never at one time with empty hands. The staff were working overtime. There were staff there that weren't due to be in, but they were there helping in order to get the place set up and to try and bring it up to their usual standard. And they were so apologetic that this is not what we are used to. "We are so sorry. The rooms are not nice, the rooms are a horrible colour. There isn't a bed for the parents." At one point, one of the auxiliaries stuck here head round, "Has he got a bed? Have you got a bed?" It was chaos.

They were the ones that were wheeling the furniture along the corridor. So, there's a conjoining corridor between the two buildings that runs from the oval shape all the way along and it brings you in at the bottom of the elevators to then go up in the lift to 6. And they were the ones that were pushing all of the furniture along that corridor. So, everything came with us. The big, relax-y chairs, which is a Schiehallion only thing. You don't get the reclining chairs in any of the other wards. The wardrobes, the bedside tables, everything came with us. Because of course, they were transferring patients with their stuff in them, as well, but even the empty rooms, the stuff came.

Q So, a procession of equipment --

A I'm sure it would've been a sight.

Q -- and patients.

A Yes. I'm sure it would've been a sight to see. But they were all exhausted when we got there. Imagine moving house with an infant and then imagine it with 20 patients that are as needy as infants.

Q Now, at paragraphs 109 and 110 - we don't need to turn them up - of your statement, some correspondence that you received about the time of the move to Ward 6A. And I wonder, Ms Ward, if we could maybe just turn the correspondence up. It's in Bundle 3, again, and on this occasion, I think it's at page 168. (After a pause) Now we see there the letter, I think. 18th September 2018, is that the letter that you received telling you about the move?

A Yes.

Q This is pro forma.

A Uh-huh.

Q Yeah. I'll just read that out, shall I?

"We appreciate that you have

been experiencing disruption whilst we have introduced an enhanced cleaning programme. As you may be aware, we initially experienced a build-up on material known as 'biofilm' in the sink drains in Wards 2A and 2B. This is the same sort of biofilm we get in domestic sink drains, but as the patients in these wards are being treated for cancer, their immune system is compromised, and they are more susceptible to infection.

Today we have introduced a new cleaning product called HyZen to clean the drains. HyZen is a hard surface disinfectant, effective against bacteria. Whilst this will work in the short term, longer term we require a permanent solution. This will require us to temporarily transfer Ward 2A and 2B to another ward (inaudible) QEUH Adult Hospital. This will provide an opportunity (break in audio) drainage and technical experts to undertake comprehensive investigation and complete any remedial works required.

We're working to make this happen as soon as possible (inaudible) keep everyone in the

> two wards fully updated on our plans as they develop. As this only affects immunocompromised patients, no other patients at the Royal Hospital for Children are affected.”

And then it seems to just stop. And then it goes on to say:

> “Thank you for your cooperation (break in audio) to ensure the highest standards of care (break in audio) treatment continue to be provided for your child.”

Do you remember receiving that?

A Yes.

Q How did you feel about it?

A Well, it was giving us in writing what we had already been told at day care and with our meeting with Dr Ronghe.

Q Yeah.

A To be honest, at that point, we felt we were more informed than anyone else because our child was one of the children who’d had the biofilm infection. We’d been told more than anyone else. For some parents, that was the first knowledge they had of it.

Q Yeah. So, this wasn’t a bolt from the blue for you.

A No.

Q And indeed, presumably, it gave you some comfort.

A Well, yes. The fact that they were gonna do something about it and that they were attempting to fix it.

Q Yeah.

A I mean, you see how scruffy the bit of paper is? Sorry, the photograph, the paper’s scruffy because I was handed it at day care --

Q Yeah.

A -- while also dealing with [redacted]
.

Q Yeah.

A So, it was just, “Oh right, okay. Next thing.”

Q Now, on the same occasion, I think, according to your statement, you received a second letter.

A Yes.

Q Ms Ward, can we go to the next page, please? (After a pause) And that’s dated the 7th of September 2018, but are saying that that was handed over to you at the same time --

A Yes.

Q -- as far as you can recall?

A Yes.

Q And that’s --

A They were stapled

together.

Q They were stapled together. And it says:

> "Due to ongoing cladding works on the QEUH site, alternative access arrangements are in place. All children and patients should utilise Car Park 2. Entrance and exit to our Hospital for Children should be through QEUH side entrance discharge lounge. Discharge lounge entrance is opened at 6am, closed at 9pm. (Inaudible) applies Monday, Sunday. Outside these hours, access can be obtained via emergency department RHC."

It then says:

> "Building materials can pose a risk of infection. Appropriate measures will be put in place to protect any child at risk as a precaution."

And then:

> "For information regarding access to car park, discharge lounge, please refer to map overleaf."

We'll look at that in a minute. Can I just ask what you took from the penultimate paragraph?

> "Building materials can pose a risk of infection. Appropriate measures will be put in place (inaudible) any child at risk as a precaution."

What did you make of that?

A Honestly, at that point, "All right. Another thing. All right. There's something else wrong."

Q Well, did you know what it was that was wrong?

A No. Just that they were doing works on the cladding outside and because of that-- But that had already been happening. The cladding works had been happening most of our time at the hospital. When we were in surgical ward, the playroom has doors that open out onto a roof garden. Well, that was locked. You couldn't get out onto the roof garden because of the cladding works, because they were working overhead.

Q What was the issue with the cladding as you understood it?

A I guessed it was something to do with Grenfell and remedial works happening for fire safety. I assumed that. I never asked the question, and it was never clarified.

Q And it was your assumption that it was something to do with that work that posed a risk of infection, is that right?

A Yes. Angela, who is the staff nurse at day care, is the one that gave us these letters and she said, "Just dust particles and things like that. It's just not worth risking them." "Okay, Angela." And she's amazing, so she says do it, we did it.

Q Are we also to understand, though, Ms Gough, from your statement, that this wasn't the only issue to do with the building at this point that was being flagged up? Was there also an issue about a window falling out?

A Yes. That happened in the early days. I didn't put that in my diary of exactly when it happened. I think it was maybe the first week of [redacted]'s treatment. And so, a window fell out of the adult hospital and landed on the pavement outside. It was reported in the press. And to be honest, we saw it reported on the press before we saw the evidence at the hospital 'cause we were in the building at the time. So, ultimately, then, there was scaffolding all around the front of the adult entrance, and there was scaffolding all around the front of the children's entrance to the hospital.

Q Okay. So, windows and cladding. We go to the next page, please, Mr Ward, just to complete this part. (After a pause) Thank you. And is this the diagram, or map, that was attached to the letter?

A Yes.

Q And, even though not entirely clear, is it fairly obvious that, by reference to the arrow, that's where you were to access --

A Yes.

Q It's the adult hospital front?

A The adult hospital, yes.

Q So, are we looking at, effectively, a side view of the adult hospital here?

A Yes.

Q Yeah. In other words, to the right-hand side of the star would be the main entrance?

A Yes.

Q Yeah. Thank you. We can put that to one side. Thank you, Ms Ward. So, thinking about where things stood at this point, the issues that you'd experienced on Ward 2A with the shower, with the water, issues that you'd experience on 3B, life-endangering events. The now closure of Wards 2A and 2B, being moved to the adult hospital, an issue with cladding, an issue with windows, possible risk from the work being done on the cladding. At this point in time, how did you feel about the hospital?

A Anxious about every single admission. And the anxiety levels just kept rising. The fact that I was still on the bounce-back from witnessing [redacted]'s, let's call it "near-death experiences", I was just running on pure adrenaline at that point. Pure adrenaline.

Q And you didn't know at this point when [redacted]'s treatment was going to conclude.

A No.

Q Or, indeed, how it (inaudible) conclude.

A Yeah. Are we gonna get through this? And always trying to find the rainbow. That became our war cry: "Find the rainbow. Look for the rainbow." Trying to stay positive, as I'm sure you got from Cameron yesterday. We look for the good. We look for the half-full approach to everything. And it was, "Right. What's next?" I didn't spend an awful lot of time going back over anything that had happened. It was, "Right, that's done. What's next?" The next thing's chemo tomorrow. "Right, okay, have we got the bag packed? Are we ready to go?" The next thing's a possible spike tonight. "Have we got the bag packed? Are we ready to go?"

And at that point, when the movement was all happening, and the fact that we had to come in the different side door, which was lengthy walk, I took [redacted] in on a spike. Because at that point we were still tag-teaming. "Oh, I'll take him this time, you take him next time." And I couldn't manage him into the building because it was too far to walk, and he was starting to show-- One of the side effects of vincristine is that it damages the nerves in the feet, and so children quite often, if they've had chemo-- We were warned to look for the "duck walk", so the foot will flop down because this tendon-- Sorry, I'm using my hand, but this tendon in the foot has been damaged. The nerves have been damaged. And you get pain in the legs, and that's just a common side effect, I think.

So, [redacted] was struggling to walk any great distance at that point. So, me taking him in meant I didn't have the strength to carry him and the suitcase with bottles of water 'cause we couldn't trust the water. We took our own bottles of water, I should say, because [redacted] didn't like the hospital-supplied water. It was very salty. So, we had to-- For one of the brands, we had to bring our own Highland Spring 'cause that's the only one he could palette. So, we had to take our own water for him. We drank the hospital provided stuff, but he couldn't. So, when we arrived, there would be three litres of water in the suitcase for him.

We had to take that with us, and I couldn't carry that and him.

And when we to come in the discharge lounge, you had to walk in past people who were using it as a smoking point. So, people would come out of the building, they'd be sitting in wheelchairs, they'd be sitting in their dressing gowns, and that's where they went to smoke. It was patients. That's where they went to smoke. So, to get in that ramp, you had to go through a gauntlet of smokers. Which [redacted] was very vocal about. "Why are these smoking, Mum? That's silly." "Shh, don't have an opinion, [redacted]." Typical seven-year-old that knows what's right and will tell everyone that they're doing it wrong.

So, to go in that door and then have to walk all the way through the adult hospital, all the way through the adjoining corridor, to then go up to Schiehallion for treatment. That meant that was it, Cameron had to be the one that had to take him first whenever he spiked.

Q I'm gonna ask you - it'll be after lunch now, I suspect - a bit about your experiences in Ward 6A. But, just maybe to complete your evidence before lunch, I think we can see from your statement, at paragraph 111, I think it is, that what you had anticipated might be a four- to six-week move then became a three-month move, and eventually a year. (Break I audio) was what you anticipated. And in fact, I think you'll be aware that Ward 2A and Ward 2B are still not open.

A Yeah.

Q And in the meantime, the Schiehallion Ward, as you've already said, was effectively moved to Ward 6A in the adult hospital, and that would be [redacted]'s point of contact going forward.

A Yes.

Q My Lord, I am going to move to another chapter now. So, I wonder if that's a convenient moment to break before lunch.

THE CHAIR: At least according to my watch, it's dead on one o'clock. So, sounds very well-managed timing. Ms Gough, we'll take an hour for lunch.

A Okay.

THE CHAIR: So, if you could be back with us for two o'clock.

A No bother.

THE CHAIR: And we'll resume.

A Fantastic.

THE CHAIR: But first-- (Inaudible).

(End of Morning Session)