SCOTTISH HOSPITALS INQUIRY

Hearings Commencing
20 September 2021

Day 2

Tuesday 21 September 2021

Afternoon Session

CONTENTS

14:00

THE CHAIR: Good afternoon, Mrs Gough.

MRS GOUGH: Good afternoon.

THE CHAIR: I think we're ready to resume. Mr Duncan?

MR DUNCAN: Thank you, my Lord.

Gough, Mrs Colette
Examined by Mr Duncan
(Cont'd)

Good afternoon, Mrs Gough. I was going to move on and ask you some questions about your experiences and indeed [redacted]'s experiences of Ward 6A. You showed us earlier, under reference to the plan, how you required to gain access to Ward 6A. I wanted to ask you something else before we really moved to 6A, specifically about the hospital. Mr Gough, yesterday, gave some evidence about the surroundings, the layout of the campus, and you mentioned that there was water treatment works in close proximity to the hospital. Is that something that you were aware of at the time that you were attending the hospital?

A Yes, definitely.

Q And how were you aware of it?

A The smells. Smells, and I talked earlier about having a headache for that first couple of weeks with the heat, and one of the symptoms that I have when I have a migraine is a heightened sense of smell, and smells have a much more powerful impact, and the smells would make me nauseous. And then subsequently, when [redacted] was feeling nauseous because of his chemo, it would make him feel sick.

Q And was this just outside -- when you were in the carpark, for example?

A No, no. There were certain rooms and certain wards where you would get whiffs of it every now and again. The most prominent one that I remember was when we were in the PICU because we were sitting in a bay with four beds and suddenly the whole room was filled with the aroma of sewage, and I said to the nurse, "What is that?" She said, "Oh, it's the treatment works." And apparently, cyclically, twice a day, when the air conditioning does something, twice a day it gets flooded with that smell.

Q And did you indicate a moment ago that it also impacted upon ?

A Mm-hmm, yep.

Q In what way?

A He was very aware of it, walking into the building. "Oh, what's that smell, mum?" Again, a heightened sense of smell because he was already feeling nauseous.

Q Yeah.

A And I guess that kind of seedy feeling, if you're already feeling seedy, that's going to send you over the edge. There was one particular day when we were in the CDU, which we haven't got to yet in the timeline -- but, when we decant from 6A back to CDU, you could smell it there. And that one day I had a migraine the whole day, to the point where [redacted] got kicked out the bed to let me lie down to try and shift it, and the smell that day actually made me be sick. It wasn't just nausea; I was sick multiple times.

Q Do you know from conversations with staff or with other parents whether this was something that other people were aware of?

A Yes, it was much talked about in the corridors whenever there was a wait. Whenever you could smell it, it was always "Oof, it's strong today."

Q Do you have any concerns about it beyond the smell and the effect that it had upon you?

A I didn't give it that much thought during treatment. Like I've intimated we were very much of "What's next" sort of attitude just to keep on going. With hindsight and having spoken to a number of parents after treatment, it made me more concerned and actually I then drew the line of "Oh, what are treatment works? Plug and drain issue, water issue -- why did nobody draw that line yet?" Well, it took me a while to draw that line because I wasn't really giving it any thought, I was focusing on [redacted] and his treatment, but we did then raise questions of what facility did they have in place to make sure that there was no backwash or-- I don't know the technical phrasing of it, but to make sure there was no cross contamination on the hospital site?

Q Thank you. I want to move then to start to think about Ward 6A which, as you said earlier, really became, as it were, [redacted]'s point of contact for his outpatient care in late 2018 --

A Yes.

Q -- or at least it was supposed to be. And you told us earlier about accessing the hospital via the side entrance, and you gave evidence about having to walk past people smoking and that sort of thing. How did you get from, once inside the hospital, to Ward 6A itself? Did you go up the stairs or what?

A Not usually. [redacted] couldn't do the stairs. He didn't have the strength in his legs to climb the stairs, and by this point in treatment, maybe about two weeks after the 6A move happened, we ultimately ended up with a wheelchair for [redacted]. So, it was elevators --

Q Yeah.

A -- and there were three elevators in the bank, and you had to stand in a queue with all of the other patients and visitors, and you had to wait for your turn. The way that it works is you push a button telling the machine which floor you want to go to and then it allocates you A, B, or C. So, you have to stand and wait and then get in the correct elevator that will stop at that floor.

Q And was there an allocated lift for immunocompromised children going to 6A?

A No. Not at that point. That came in much later, after the meetings had started, when parents had raised concerns.

Q And was there any limit on the number of people who would be in a lift?

A No. Well, I think “13” maybe would have been written on the lift -- rings a bell, but don't quote me on that.

Q And you would be there with [redacted] in a wheelchair?

A Mm-hmm.

Q And where there there people in the left who were unwell?

A Yes, yes, anyone; all members of the public, visitors, people going up and down from wards. There would be other patients in jammies in their wheelchairs. There was one instance where we were in the lift with two police officers and someone in handcuffs which interested [redacted] greatly, and it was “Don’t ask any questions, [redacted], just wheesht.” So, you just had to share it with whoever was there.

Q Can you tell us a bit about the facilities on Ward 6A? Mr Gough, yesterday, helpfully walked us through the plan, and I don't propose to do that again today, but what kitchen facilities were there, for example?

A None. I would say, talking about facilities, lack thereof, really. There was nothing. It was just an empty ward.

Q Well, let's maybe take it in stages. What did it look like compared to what the actual Schiehallion ward looked like? By that I mean --

A It was an adult unit.

Q Yeah.

A It wasn't child friendly at all.

Q So, décor?

A There were some stickers put up by the staff to try and make it child friendly, but it was darker in tone; the paint colours were darker. The rooms weren't set up for having long-stay visitors. There wasn't space in the rooms, the rooms were smaller. There wasn't the space within the room because of all the furniture and with the addition of a fold-up bed compared to the pull-down bed, which meant even when it was put away it was still a big, cumbersome thing in the room, and there was no wall to push against because there wasn't any space, so you ended up having to work around it all the time.

Q What about play facilities?

A Nothing.

Q Nothing at all?

A The staff tried to create a small play area in the corridor, which was two child-height tables, so preschool height tables, small squares with two little chairs on either side. So, there was space for four children or two children and two adults to sit, but you were in the thoroughfare. So, if [redacted] was sitting at the table and I was kneeling beside him, as I would do, as soon as anyone came in, you had to stand up to let them go by because you were blocking the corridor. So, not ideal at all.

Q Mr Gough, yesterday, described how, if you were going to day care, you in fact had to walk past the whole of the in-care unit, is that right?

A Yes. Yep, you had to walk the length of the unit to get there.

Q What effect did that have, if any, on people who we were in in-care?

A Well, there's constant traffic --

Q Yeah.

A -- through the ward. There’s a higher risk of infection. One of the protocols for a phone call to go into the word is a high temperature, another one is a chicken pox exposure. So, because of the chemotherapy, [redacted]'s immunity to chickenpox was wiped out. And so, if he is sitting with someone with a cold sore at this proximity for more than 10 minutes, we had to phone the ward. If he was in the room for 15 minutes with someone who had chickenpox, we had to phone the ward -- and that was something that we had to relay to the school when [redacted] eventually did go for the odd day at school. And after [redacted] finished his treatment, we had a call from the school to say that a wee boy that he had sat next to the day before had then phoned in with chickenpox. The school were brilliant, absolutely brilliant at informing us of anything like that -- obviously, always keeping confidentiality of the other child, but they were erring on the side of caution all the time. They phoned me anytime there was anybody being sick or any sort of bug.

Chickenpox meant we had to go into the ward to get an injection of antibodies in order to protect [redacted]. And to get to day care, we had to walk the length of the ward, so by just taking him in there, potentially, he was exposing everyone on the ward to chickenpox. That's not very clever.

So, when we went in, I said, "[redacted], walk behind me. Don't speak to anybody. Don't touch anything" because I was aware of how dangerous that (inaudible). And when we got to day care, they knew we were coming and we were taken straight into a room, and the nurse that gave him the injection, which is a really painful one -- he cried after that one because it was really painful, and she said, "It is a nippy one. Now you stay

here. You cannot leave this room until someone escorts you out to make sure that the hallways are clear" so that nobody would inadvertently walk into him.

Q I am sure we will all remember your very vivid description of your first impression of Ward 2A, Schiehallion unit, and of [redacted] and you walking in and seeing children moving about the corridor playroom.

A Mm-hmm.

Q I'm sure many of us will have taken the tenure (?) of what you were saying that, for [redacted], there'd be an impression real childhood is here --

A Yes.

Q -- happening. Ward 6A?

A Everybody was stuck in their rooms because there was nowhere to be. You couldn't freely wander up and down the corridor the way that you could in 2A because the day care traffic was constantly going in and out. You were stuck in your room in what is isolation. Now, we were never put into "source" -- and that's a new word, I don't know if any of you have heard that one before. If you're put into source, it meant that your child had some sort of vomiting or diarrhoea episode, and sometimes that was a reaction to chemo, sometimes it was vomit-y bug or a diarrhoea bug, because if it was a vomit-y or diarrhoea bug -- that's so infectious, you're not allowed out their room. So, if you were put in source, a big yellow sticker would be put on your door, and no member of staff would go in there without protective gear on, and they weren't allowed in the playroom and they weren't allowed to wander the corridors. They could go out of the room and go straight out of the ward to go out and get fresh air outside, but they were contained in their room.

We were never put in source because [redacted] never had vomiting or diarrhoea like that as a reaction to chemo, his was a temperature -- that was how he reacted. But, when we were on 6A, basically we were all in source all the time because there was nowhere else to go. So, they ended up being “plugged in” more, and by that I mean using tablets to keep them stuck in the room ‘cause, remember, it is a smaller room with more furniture and more clutter in it so there's not even space to move around the room freely.

So, really, he became much more sedentary, and that's not something that you want when you're trying to fight against leg muscle atrophy. We were trying to keep him moving as much as we could.

Q What effect did that have upon [redacted]?

A He became institutionalised.

Q What do you mean be institutionalised?

A He became withdrawn. He became less able to communicate with other children because he only spent time with adults. He spent time with Cameron or myself or the nurses and doctors. He became the centre of the world in that wee room. He got his own way. He was a spoiled brat, which is something we worked really hard against, knowing that we would have to deal with the fallout afterwards. We're trying to remind him that, you know, “Your sisters are here too” and trying to keep them on side as well.

He became less able to interact and engage with the world outside, and it's something that I think we can all relate to more, having had COVID in our lives for the last year and the isolation that everyone in the country has complained about, and the mental health focus that has been raised in the last year-and-a-half for the whole country. We were already there; that's what we were like for his second part of his treatment once we moved up to 6A.

Q Okay. Now, I want to move on a little to a couple of experiences where [redacted] required to be admitted --

A Mm-hmm.

Q -- but there was no room in 6A. I'm gonna mention two in particular. First of all, I think in November it was, [redacted] was admitted to the paediatric cardiology unit --

A Mm-hmm.

Q -- and I think it's fair to say you've got good things to say about that unit? Is that --

A Definitely.

Q -- fair?

A Definitely.

Q To paraphrase your statement, I think you say it was attuned to the needs of an immunocompromised child, and you give particular praise to the cleanliness on the ward, for example.

A Mm-hmm.

Q There was a later occasion, I think, where [redacted], again, couldn't get into 6A and he was admitted to the paediatric orthopaedic ward beginning of December, and -- for those following the statement -- that begins around paragraph 125. Mrs Gough, would you like to describe to us your recollection of that admission?

A The first part of that admission I was home base, so I was getting phone calls from Cameron reporting first of all, that he was in CDU. He would send a text or a phone call, say “Right, we’re in” because he would always let me know if they were in and that he was hooked up and that the antibiotics had started because I was sitting at home anxiously waiting to know that that had happened. “We’re in. They can't get the line in”, and that means that they couldn't get the gripper needle into the port. Now, I know Cameron explained it a little bit yesterday -- that it sits under and it's like little lapel pins. So, take a lapel pin and multiply it by three, that's how long the gripper needle is. And, when they miss the port, they're going directly into his chest. So, I said, “How many times did they try?” “They've tried five times, and with each miss, he lets out a yelp.” I've already said, as well, [redacted] doesn't cry -- not that kind of child. He only really complains if it really hurts. So, for him to let out a yelp, that can't have been fun for him.

So, at this point, I am anxious because first of all, why can't they get access to that port? That then puts us onto a higher level of anxiety of “This could very well be another line infection because, if they can't get into the port, what's wrong with the port?

Has the port gone already? Does that mean another surgery? Does that mean another line infection? Are we going right back to where we were in September?” I didn't sleep a wink that night while he was in.

“Been transferred to ortho.” “Okay.” “We’re in ortho, they’ve gone with a cannula just to get the antibiotics started.” “Right, that's fine. That can't have been fun.” “No, it wasn't.” “Okay.” In ortho, then, he phoned me to say that it’s terrible, they're just not coming; they're late with obs, they’re late with the paracetamol. “He's in rigour and they're not coming.” And I said, “Well, phone Schiehallion. Phone into the ward and get one of them to come if ortho weren't answering.”

He had a terrible night, terrible night while there. By the time I got there, the spike really was over. You know, things had calmed. I mean, that was the difficulty of it being that Cameron was always the one that went in first; that was the acute point of the spike and the acute point of the anxiety. I would always come in as the second bit and “Right, okay, the spike’s finished, so you go home and get some sleep and I'll take over.” And I have never seen Cameron look as broken as he did that morning from the

lack of sleep that night, from the fact that he couldn't relax at all. He did not feel that [redacted] was being cared for.

I'm sure Cameron said yesterday, we're not pushy people, we are not people that shout, but he was angry and worried that he wasn't getting cared for. I think ultimately Cameron put him on his back and took him up to day care, “Right, come on then, let's go get this line in.” And day care got it in the first stick because that's what they do every day. They're really good at getting the children into the right position.

Q And that's because on 6A, while all the infrastructure may not have been there, the staff were.

A His team are. Yes, they're the experts at this --

Q Yeah.

A -- but, because there aren't enough beds up there --

Q Yeah.

A -- we’re bumped.

Q Now, what was your feelings about the hospital by this stage?

A Wearied by the fact that we were getting bumped out of Schiehallion and “Ah, right, okay. Where are we going now?” Ask an oncology parent where you can get a cup of tea at every point of every day in that hospital, and we'll be able to tell you because we know where to go for everything.

To some extent, being back in the children's hospital was a boon because at least then you're in a room that's set up for children: toilets are the right height; the sinks are the right height. Whereas, when you're in the adult ward, it's not -- it's set up for adults: the toilets are slightly higher; the sinks are slightly higher, and that makes a difference when you're only 4ft -- makes a difference when you're only 5ft. And that's something that, when we were then in ortho, "Well, at least we're in the children's hospital."

But when I came in that next day, Cameron was broken looking. And I had to bring the girls with me because we were going for scans, so the girls were coming with us to go for scans -- and we had to take ourselves to go and get the scans, the ortho team didn't interact with that at all. These were pre-scheduled. We would have been coming in as an outpatient for that. Had we been on Schiehallion, I assume that someone from Schiehallion would've escorted us to those scans, but with ortho it was just, "Right, we're away for our scans. We'll be back when we're back." A very remote level of care.

Q And I think Mr Gough described reaching a point where it got beyond the "Let's hope we're not in over Christmas."

A Yeah. We bounced back in the following week because [redacted] had a skin infection, which is because he was so run down, and while the nurses in day care were treating him, "How's it all going?" You know, by this point we are getting weary. We're getting battle-weary because it's been such a long journey till there, and it's only been three months, and saying to them, "Oh, that ortho stay was brutal, absolutely brutal." And relaying to them the anxieties and the phone calls home, and them saying, "Well, that's awful. That's terrible that that was happening." They were phoning up here and we wanted to go down, but we couldn't go down because they are in day care, they're dealing with the day care patients.

So, that's why Cameron then put [redacted] on his back and took him up to them, because they weren't free to go down and administer at the other side of the hospital. And that was the day that we were saying, "We've gone from panicking about Christmas, him being in hospital over Christmas, to being not in Schiehallion over Christmas" because the unknown and not knowing where you were going to end up was just an extra layer of stress.

And to give you a bit more context, I'm planning Christmas for three children; that's stressful every year for every family, we're doing it with a child who may or may not be in hospital. It would actually have been easier if he was just an inpatient, because then we would’ve known. But planning for Santa to come, either here or there, “How do we do it if we’re here? How do we do it if we’re there? How do we do it if we have to go between at midnight? How do we do it if we meet Santa's sleigh in the middle of Glasgow?” That's all the things that we're planning for at that point. And now we're just saying, “See if we end up in. Let's just be in Schiehallion, at least then we know what we're dealing with.”

Q So, as long as you get to 6A?

A Mm-hmm, because at least then we can trust the staff.

Q I think we can see from the timeline that, in January 2019, [redacted] did require to be admitted again.

A Mm-hmm.

Q But, by this stage, there was now an issue with 6A itself --

A Mm-hmm.

Q -- is that right? I wonder if we could go to your statement again, please?

A Yeah.

Q Ms Ward, it’s at Bundle 3, page 136, and it’s paragraph 134. And once again, if you don't mind, could you read out --

A Sure.

Q -- your paragraph 134 to us, please?

A

> “Once we got into January 2019, [redacted]’s chemo continued and he spiked on 17 January and was admitted to 6A via day care. At this time there was a fungal issue on the ward which was being blamed on pigeon poo. We had only heard about it on the news and saw it on the chat among the parents on the Schiehallion parents’ page…” by that I mean the Facebook page.
>
> “We thought ‘what now?’ and that this was ridiculous. There was a lot of anger on the Facebook page that we hadn’t been given any information about this from the hospital. When we went into the hospital on that occasion, there were HEPA filters in the corridors and in every room.”

Q Can I just pause you

there? What's a HEPA filter?

A I don't know. I don't know what it stands for. It's an air filter. I don't know what the "H-E-P-A" means.

Q What are you describing, in terms of what it looked like?

A A box this height, by probably 30 centimetres square --

Q Right.

A -- white, constantly whirring.

Q Designed to do something (overspeaking) --

A To filter the air.

Q Do you want to keep reading?

A Yeah.

"We were given very little information from the nurses on the ward about what was going on. We were not told anything official by the hospital at this point, we were only being told by Angela, the day care staff nurse, that there was a fungal issue in the hospital and the filters were there as a precaution because the kids were immunocompromised and were too precious to risk. She was the person who was giving us all the information at this point and the poor woman was in the firing line

every time. It was about a week later that we got a letter from the hospital telling us about the pigeon poo. This letter is dated 23 January 2019 and I have a copy which is attached to this statement.

I think we only got this as the parents were so angry about the lack of information and what we were hearing in the press. That was the first instance of the hospital deliberately making sure everyone got a copy of a letter. January 2019 was the point that they started giving us formal headed notepaper letters. We got a copy at day care and it was also posted to us so it had obviously been posted out to every patient on the unit. This letter said that people had been infected. This is what it said --"

Q I'm just going to pause you there because you have provided us with a copy of the letter.

A Mm-hmm.

Q Ms Ward, could we go, please, to -- in the same bundle -- page 171? Now, if I just read that first paragraph.

A Mm-hmm.

Q

"Dear parent, you will have

seen recent media coverage regarding two isolated cases of an unusual infection in the Elizabeth University Hospital, where Ward 2A has been temporarily relocated to, and about the ongoing control measures which have resulted in no other cases." Had you seen media coverage --

A Yes.

Q -- that indicated everything that's in that first paragraph?

A Yes.

Q That there was two isolated cases, and that there had been ongoing control measures --

A Mm-hmm.

Q -- and that there had been no further cases?

A Yes.

Q And do you want to just read the rest of the letter to us, please?

A Sure.

"I wanted to write to you personally to offer reassurances that we are taking these issues very seriously and to apologise for any anxiety this situation may have caused. At present, our clinical management and infection control teams are

focused on ensuring a safe environment for all of our patients and are actively managing this instant. As you will have seen from media reports, we are investigating two isolated cases of an unusual fungal infection, Cryptococcus, which is linked to soil or pigeon droppings. These cases were identified in December and the likely source detected and dealt with immediately. We have put in additional control measures, and these have proven effective as there have been no further cases. During our detailed investigations into these isolated cases, a separate issue was identified regarding shower room sealant issues that are now being urgently repaired. While this is being repaired, some patients have moved to another ward area. Although your child is not currently receiving treatment as an inpatient and not directly affected by these ward moves, I want to give you my personal assurance that we are focused entirely on addressing these issues speedily and on the continued safety of our patients and their families. If you would like to discuss this further with one of the management team, please contact Kevin Hill, Director of Women and Children's Services, on 01451 6518 who would be happy to answer any questions.

Your sincerely,

Jane Grant, Chief Executive --

Q Thank you, Mrs Gough.

A -- NHS, Greater Glasgow and Clyde."

Q What did you understand from this letter?

A That there was another issue. Something else! We'd heard about the pigeon droppings on the news, and now there's something going on with the showers -- something going on with the bathrooms.

Q Does the letter indicate to you that it was actually during an investigation into infection, possibly from soil, possibly from pigeon droppings, attention turned to the showers?

A Mm-hmm.

Q And a further issue emerged in relation to that?

A Yes.

Q And what did you understand the further issue to be?

A That the seals between

the floors and the walls -- So, the wet floor comes up a few centimetres from the floor and the seals at the top of those were coming away, leaving a space for bacteria to grow, and fungus to grow. So, they were going to rectify all of that.

Q Now, you speak about this in your statement. In fact, it's at paragraph 160. We don't need to go to it. Am I right in understanding that you yourself had actually seen signs of this?

A Yes, uh-huh. The rooms, when we first arrived on 6A, didn't look like rooms in a shiny new hospital. They were well-used and not in great state of repair. Most of the TVs were broken, the place just looked grimy. It wasn't as clean as Schiehallion was. And by that, I don't mean it didn't look as clean; it was grimy.

Q And did you see signs of repair work going on while you were in 6A?

A Mm-hmm. While we were in, there were some rooms that were closed off with orange plastic taped over the doors, and you heard thumping and banging happening inside. So, there was work happening and they were in a sealed space so that none of the debris escaped.

Q Now, as at this point,

January 2019, what was your assessment of the hospital's communication of these issues with patients and families?

A What communication? The communication was terrible. This was the first time we'd been given a letter, and the only reason we got this letter was because there were a lot of angry parents phoning the ward, phoning day care, being invited in to have meetings with Prof Gibson. I've never actually met Prof Gibson, even though she's the Head of the Ward because she wasn't our consultant.

Our consultant was Dr Ronghe. He came to meet with us on this visit to tell us as much as he knew and to explain more of what's said in the letter that, “We're trying our best to take care, and this is all just because these children are high risk, but actually, you don't have to worry about anything. The fungal issue has been dealt with. Now, this issue with the showers is another issue we have to deal with.

And to do that, we may have to move you out again.”

There was a bit of chat on the parents’ page about some prophylactic antifungal medication and Dr Ronghe assured us that [redacted] didn't have to have that because he was not an inpatient for any great length of time.

Suspecting as he did that our stay that time was just going to be another 48-hour stay to rule out a line infection, that he wouldn't have to take it.

Q So, about the same time as the issue with 6A is emerging, there’s another issue emerging, which is that some patients are being given prophylactic medication, is that right?

A Mm-hmm.

Q In your statement at paragraph 188, for those who want the reference, I think the way you put it is you indicate that the hospital was, if anything, downplaying these issues as you saw it.

A Very much so. And even the wording of the letter that, “… unusual … We're doing it because these children are high risk,” and that, “It's okay, you don't have to worry about it. We're just doing this as an extra barrier of protection.” That it’s nothing to be concerned about. But it wasn't the hospital that were telling us that, it was the frontline staff that were having to tell us that. And it was unfair, we feel, that people who are experts in oncology, very learned, very experienced, are having to do PR work and spend their whole day answering the phone doing PR work.

Q Yeah.

A That's not their job.

Q Let's go back to the 8th of August 2018 and the information that you were given on that day. Just think about that, what you told us earlier, detailed information about what (inaudible) planned for [redacted]. What lay ahead. What you need to look out for. What would you need to do to manage that? Pair that to the single sheet letter that we've just looked at. How you pair and contrast the level of communication?

A It's chalk and cheese, isn't it? This is, “You don't need to know this. You don't need to know this. We are dealing with this. Be gone, young child.” They were patronising us, really. And that was offensive because there were parents on the ward, and you have to remember that we were running on anxiety levels of 90. We’re up to here with all of the things that we're dealing with because their children are dealing with cancer, and now we've got to worry about the building and pigeon droppings. Are you kidding me?

And now we have to worry about the showers not being right? So, is it safe to use the shower? Is it safe to breathe in here? Is this fungal spores? Do we need to worry about kids now ending up with lung infections? I don't know. I'm not a specialist.

But I know that the extra levels of stress for all of us got to breaking point and the amount of chat -- Cameron kept himself quite remote from all of the Facebook chat. I joined the Facebook page in order to be able to communicate with other parents. And, in fact, we all encouraged each other to use it now that we were in 6A and couldn't communicate as easily. But the panic that was happening among all of the parents at home watching the TV and saying, “Oh God, now what? We've got an appointment tomorrow. Is it safe to go? I'm really worried about taking my child into that now.” And I would say that was the point that the switch happened for me, where I didn't really trust it anymore.

Q I think it was about this time that -- you’ve touched on this earlier in your evidence today, in fact -- about this time that effectively, [redacted]’s inpatient care, if he required, it would be in the Clinical Decision Unit, is that right?

A They moved the whole Schiehallion Unit downstairs to CDU, yeah.

Q And I think to be fair, in your statement, you identified that there were advantages to you from that point (inaudible).

A Back in the Children's

hospital. Yes.

Q Yeah. And on the ground floor, as well.

A Yes.

Q But, did that take away from broader concerns that you had? The heightened anxiety.

A No, because we're still in a room with water filters. We're still in a room with the smells, 'cause down in CDU, you can smell the sewage works. You're aware of going out into the little play area, because there was a wee play area there, which was wonderful, but chatting to other parents and hearing more of their stories, or their experience of this and all of the decanting -- We're isolated. We're in our little room, so we are not aware of the impact it's having on other people. And hearing the other stories, then, it's, "Oh, this is as bad for everybody. It's not just us. The other parents are carrying this extra load as well." Cancer treatment's hard enough, don't make it any harder. And this was just another layer of hard. Another extra thing to carry.

Q Now, we're moving towards the end of [redacted]'s treatment. And I think in February 2019 you describe a return to 6A. By this stage, Schiehallion had been located back in 6A, is that right?

A Yes.

Q And there was an admission, I think again, with a temperature spike. It's paragraph 141 for those who are following the statement. Is there any sign of improvement in the bathrooms?

A Didn't notice any difference.

Q Yeah.

A None at all.

Q And I think, just to pick up on a point of detail, according to your statement, it's by this point that this issue about the use of prophylactic antibiotics has started to emerge. And was that in the discussion amongst parents?

A Yeah.

Q I think in March there was a return to Ward 3C. But you had a more positive experience on this occasion, is that right?

A We went in, ready for, "Oh, here we go." That was his last chemo push and we'd been in the day before celebrating. "Look, it's the last one, [redacted]. Last time." Taking photographs and sending them to Granny saying, "Look at me. Last one." And then we bounced in again and, "You need to go to ortho." And it was the same nurse that I had been chatting to in the December, saying, "Oh, ortho was awful," and she said, "The only space that there is is ortho." "Don't send us to ortho. Please, don't send us to ortho."

And "Always a rainbow" became a motto, but so did "Suck it up, Buttercup", which is from Moana. That's the girls' influence. "Suck it up, Buttercup." Imagine that from a four-year-old. And so, it was very much a "Suck it up, Buttercup. You need to do this." And that was one of the rare occasions where I took [redacted] in as the first hit. It was up to me to go in and clean everything and make sure that the staff were paying attention, and they did because I made sure of it. And it was a different nursing team that worked with us. I'm sure heckles were up as we came in and they recognised us.

Q Yeah.

A But there was never any animosity or anything.

Q And I think [redacted] finished his treatment shortly after that: April 2019.

I want to move on now, Ms Gough, and I'm now going through the whole of the timeline of [redacted]'s treatment. We've looked at particular aspects, and I want now to start thinking about some of your reflections, which you speak about in your statement. Let's

just start at the beginning.

A Okay.

Q You had a child who had cancer and who, if he did not receive the right treatment and care, would die.

A Yeah.

Q And it's obvious from what was said yesterday and what you've already said today and is in your statement that you are very grateful for the fact that that's not where you ended up.

A Yes.

Q And, for those of us who have not been through that experience as a parent, it must be unimaginably stressful, I imagine. You've already described the illness itself like "life-threatening", the treatment is "gruelling", and I think it's obvious from what you've said, that confidence in those to whom you entrust care, your child must be paramount. Even when things are happening that appeared to be, on the face of it, making things worse, you need to be able to trust those who are doing it. Was confidence in the hospital, something you always had?

A Yes. (Inaudible) people in the room, any experience or interaction I had had, any of the hospitals I've ever been in, I've always had complete faith in the clever people in the room.

Q Throughout these experiences in 2018 and 2019, was that confidence ever dented at all?

A Yes. I have a constant fear, and I'm sure it's a word that'll come up and you'll hear it from more than me: "scanxiety". It's every time we go for a scan -- [redacted] goes for regular checks because one of the side effects of getting chemotherapy is that you can get a secondary cancer because of it. Not a lot of people know that. That's why they're so carefully monitored all the way through to adulthood because this is a medical trial. They don't actually know the long-term effects of these drugs that they're putting into them.

So, every time we go for a scan, in the back of your mind you're thinking, "Is this it starting again? And if it is, do we have to come here again, where we really now do not trust the safety of the building?" We trust the staff, we trust the medical experts, we trust the Schiehallion team, and we're so grateful to the Schiehallion team. Do we need to do it there?

And there was conversations at the first public meetings, where a lot of the parents were coming in, and one of the questions was, "Why can't we just go back to York Hill? Is that not a possibility? Why can't we decant there instead of the adult hospital?" Because how does going from the children's hospital to the adult hospital solve a water issue when it's the same water source? How does it solve a fungal issue when it's the same campus in the same fungal issue? How does that change help and keep them safer when it's all in the same campus? It's all the same source. But moving to York Hill wasn't an option to let them have proximity to the other aspects of care.

So, to be able to be near surgery and to be near the PICU, they had to stay on a campus. They couldn't move it off campus. And I do understand that. I accept that. But 6A for a long-term fix was not a reasonable option. It was okay for six weeks. You could muckle through for six weeks, but we're now at two years of children not getting to be children in hospital. They've lost one of their European Rights of the Child: the right to play. And that, for someone in my profession, is abhorrent because they are losing their childhood. Cancer took it first, and now the hospital building has taken the other bit. And that's not fair on them.

And if we had to go back in there

-- old hindsight is a wonderful thing; we have learned so much -- If we go back in there, I will be the shout-y parent, I'm afraid. The staff are gonna hate me because I'll not let them away with anything. Don't put [redacted] through anything that he doesn't have to go through. That is so unfair. So unfair that he had to carry that load, and we're here today talking about it. We were just bystanders. It was him that did it. It was him that lived through it. My superhero.

Q I've tried to list from your evidence statement, from what you've said today, what I took to be the burdens that were in that load. Just trying to take them from the very beginning. [redacted]'s admitted to a ward at the very start where you're not allowed to drink the water, first one.

The second one is you're in a room with a child who is regularly spiking temperatures, but you can't control the temperature of the room, yeah?

A Yeah.

Q You're in a room where if you use the shower, you're going to inundate the area where the toilet is -- flood out into the bedroom, yeah?

A Yeah.

Q And then, you're in a situation where that ward, where that vital Schiehallion umbrella was, closes, and you're in a situation where you could be transferred to other wards, where possibly none of that here was present, is that fair?

A That's fair.

Q And within six weeks of [redacted] beginning his journey -- this is the fifth on my list -- in six weeks you discover that [redacted]'s running a risk of infection from the very hospital that's supposed to be saving his life, is that right?

A That's right.

Q A life-threatening risk. And sixthly, depending on which ward you were in, might not have the right staff there able to deal with that situation. And I think it's obvious from what you've described already that we're talking about a situation that deteriorates very rapidly indeed, is that right?

A 40 minutes.

Q And wherever you are -- this is the seventh one -- in the hospital, you're never very far from a smell.

A No.

Q That impacted upon you --

A A nauseating smell.

Q -- impacted upon you and impacted upon him, is that right?

A Yes.

Q Eighthly, you're in a building where there's windows falling out, or at least a window falling out, is that right?

A Yeah.

Q Nine, you then discover there's something wrong with the cladding, yeah?

A Yeah.

Q And that the work to put that right might itself run a risk, yeah?

A Yeah.

Q Ten, you're moved to the adult hospital. To get there, you have to travel past smokers, in lifts that have people with whatever illness or problem they came into the hospital with, is that right?

A Mm-hmm.

Q 11, but at least when you get up the lift, merge through the doors, Ward 6A, you're in the Schiehallion unit, you're with the staff, and then that's closed as well.

A Yeah.

Q 12, you discover that, in fact, there is an issue even in that ward to do with showers and fungal growth, I think you said, yeah?

A Yeah.

Q 13, see from the media and from a single-sheet letter from the Health Board, there's an issue. Infection, possibly from pigeon droppings, possibly from soil, yeah?

A Mm-hmm.

Q How do you feel about all of that, Mrs Gough?

A I think it's barbaric. I think it's awful, that we were already doing a very difficult journey. There's a reason that there's so much fundraising and so many charities that are there to help children that are going through chemotherapy because it's one of the hardest journeys a child will ever do, and add all that extra layer of stress, it’s actually a wonder that we didn't collapse sooner than I did. It really is a wonder when you see all that. I'm a superhero, when you put it all condensed like that, a lot to take on and a lot to carry, on top of bottles of water and games and a small child on your back.

Q On that list of 13, how many of those do you feel you received adequate communication on?

A None. None of it was adequate. And any communication that we did get was coming from the wrong people. The doctors and nurses that were treating [redacted] for cancer were not the people that should have been telling us about that. It shouldn't have been their job to take our flak. It was unfair to expect that of them, and it was unfair to waste ten minutes of my 20-minute appointment time on that when I should have been talking about chemo, when we should have been focused on [redacted] and his care, when we should have been worrying about the side-effect impact on him. When we should have been asking about how are his legs today, we were talking about pigeon poo.

Q I want to move on a little and ask you some further questions about communication, very broadly. And this is after [redacted] finished his treatment. Am I right in understanding, and indeed, should we understand from your evidence that you were one of a number of people who attended a meeting with the then Health Secretary?

A Yes.

Q And was that in late 2019?

A Summertime. Summertime, Autumn time, I can't actually tell you the date 'cause I didn't put that in my diary because I put my diary away.

Q But as far as you can recall --

A Yes.

Q -- just generally --

A I can tell you it was the Glasgow Central hotel.

Q As you can recall, and just generally, who was present at the meeting?

A The Health Minister was there, Jeane Freeman, one of her aides, a head of nursing for the government and I think it may be 12 families or parent representatives of families.

Q What was the purpose of the meeting?

A It was for them to gather information about what was happening at the hospital because there had been publicity and flags raised by some of the parents in the press about all of the massive list of things that you just stated, all of the different goings on and the lack of communication from the hospital about how they were going to make it better for the children.

Q And was there an opportunity for parents, and indeed, patients to offer their views on these things? Raise questions?

A Indeed, it was very much an open forum.

Q Yeah.

A Miss Freeman basically put it to the group and said, "Well, I'm here to listen. What do you want to tell me?" And we calmly went round the group and everybody told then of their story. And quite a few people asked questions about what's going to happen next. How is this going to be made better for the children? Can't remember the exact conversation, but it was minuted, so the minutes are available. My main reason for going was to represent the children and the fact that they had lost the ability to be children in that ward, and that there was no space for them to play and no space for the parents to support each other, aside from all of the other issues.

Q And was that something that you voiced at the meeting?

A Yes. Very much so.

Q What reaction, if any, was there from the Health Secretary to these matters?

A She was appalled by what we all told her. They weren't aware of any of it. They didn't know how bad it had got for us all. And the fact that there was more than one family saying the exact same thing, none of it could be denied.

Q Well, thinking about my list of 13 items, were some of those items mentioned at the meeting?

A Yes. Yes.

Q And --

A Our experience of [redacted]'s line infection wasn't across the board, but every family there had had some instance of an infection of some description that shouldn't have happened.

Q And are you indicating that it was your impression that Ms Freeman was hearing these things for the first time?

A Yes, very much so.

Q And why did you think she was hearing these things for the first time?

A Her statement at the end, when we all finished speaking, she says, “I am appalled at this.” She comes from a nursing profession, and she thought that the way that we had all been treated was terrible, and she was going to go and rattle some cages to make it better. And here we are, to make it better. She appointed Professor Craig Smith -- I think was his name.

Q Professor White.

A Oh, Craig White. Sorry, thank you. Professor White to be a liaison between us and herself and also the hospital. So, if we had any queries about anything that was happening, we could send them through him and he would get a response for us because parents really felt that the hospital, as an organisation, weren’t listening to us or answering our questions openly. We were fed up of hearing about things on the news, that that was the first instance of information being given. And in fact, only when it would be on the news would we get handed a scruffy press release. We wouldn't actually get told any better information than what we were hearing on the news or reassured in any way.

Q Yeah, because by the time of the meeting with Miss Freeman, my list of 13 and other well-known stories had already been in the media.

A Yes.

Q So, what was it that gave you the impression that, notwithstanding that, Miss Freeman hadn’t been aware of --

A I don't think she was aware of how bad it was, how hard it was for us all. I think when you're in it and you're living it and your attitude, like ours was, of, “Right, just keep going. Just keep going.” You normalise everything that's happening. For us, when we were going into hospital, part of our crash bag was a thermos flask so that we could fill it with hot water so that tea-jenny Cameron could get a cup of tea at three o'clock every morning to keep them going. That was essential for him to manage the night times when [redacted] was spiking.

So, we put a thermos flask in our bag, and we took a lunch bag with an ice pack in it to keep food cold because there was no access to anything like that on the sixth floor. Get a cup of tea from the café, you have to go down in the elevators six floors, if you can get in one, go get a cup of tea and come back up. That could be 20 minutes. When a child is spiking, you barely leave the room because you can't trust that they're okay. And you don't want to buzz and annoy the nurses for a cup of tea. Although, they did say, “Shout us if you need us. If you want a cup of tea, just let us know.” And they would bring a tea trolley around.

I mean, this sounds terrible that I'm really latching onto the cup of tea, but you have no idea the power of a cup of tea when you're dealing with what we were dealing with. And when I said all of that out loud to a counsellor after the fact and said, “Oh, yeah, we had a thermos flask and we had--” He said, “What? You had a thermos flask and a picnic bag in a hospital? Were you camping?” “Well, yeah, we were ‘cause we couldn't trust the stuff in the building was safe. The hospital couldn't trust the stuff in the building was safe, so we had to take our own.” In the flagship hospital there wasnae a fridge, there wasn't a kettle, because they couldn't give us a space that was safe for us to go in and use it. And we normalised that.

But when we said it to Ms Freeman, she was as appalled as she should have been, ‘cause that shouldn't be the norm. I shouldn't have to worry about that bit of it. I'm supposed to be worrying about the chemo and the chemo reaction and the temperature spike, and just the child that needs a hug from his mum. Because he's just a child, by the way. Or the child that wants to sit and play card games or the child that wants to sit and play on the Nintendo Switch with his mum, who doesn't know how to work it and he loves that. That's what my focus should have been, not whether or not the building was safe or whether it was safe to go in and take a shower or not. So, that's what gets me a bit angry about that. Sorry.

Q Mrs Gough, I think you know this is your opportunity to give your evidence to the Inquiry about how you truly feel, so shouldn't apologise for doing that I did. Now, did you and [redacted] and Mr Gough become involved in something called the “case note review”?

A Yes.

Q Tell us a little bit about

what that was, and your reflections on it.

15:00

A Because of high number of children who were contracting gram-negative infections, and from my understanding, gram-negative means that they are not treated with antibiotics easily. They are antibiotic resistant, almost. Because there was such a high number, there was an inquiry and a review of the case notes of the children on our ward, the immunocompromised children. We were told in advance that [redacted] would be part of that, and we weren't surprised to receive that letter saying that [redacted] would be part of that because we already knew that he had had a gram-negative infection. It basically comprised, then, a set of independent doctors looking over the case notes of the children involved and asking questions and making recommendations. We weren't part of it, we weren't invited to it, we weren't consulted on it until the actual review was published, and it was quite (inaudible), quite a lot of recommendations within it. But one of the main things that came out of that was that they couldn't be specific about identifying the root of some of these infections because the testing that could have been happening hadn't been happening in order to identify the root.

Q What do you mean by that?

A Had they been testing the water supply, we would know --

Q Sorry, if I might interrupt you -- who's "they"?

A "They" -- the hospital, the hospital infrastructure. Had there been-- Or the infection control team perhaps. Had there been tests and samples taken at specific points, then that information would be there for the case note review team to refer to, but those tests weren't being done. So from what I could gather from the case note review, and more clever people will talk better about it than me -- that was really good English, anyway -- had they started testing when the first red flags were raised by the medical teams or by the first instances of these infections, then they would be able to identify the ones that happened further down the line in the time frame. But they didn't start testing, and it would appear that they didn't start testing or really looking into anything until the instance of the weekend where six children fell ill, where [redacted] was one of them. And, again, this is my take on it: we were informed that [redacted] was one of six children who fell ill. We weren't told that the six children all fell ill with different illnesses. We assumed that they all had serratia marcescens, and when we read the case note review, there was only one case of serratia marcescens. So we said, "Well, that's [redacted] then. That'll be him." So there was more than one point of origin of these infections. They didn't all have the same bug. So there's more than one source of these infections, so why were they not looking into it sooner? The fact that it was in the press before we even started treatment, the fact that there were filters on taps by mid to late August -- well, why was there not testing happening at that point? Why was there not more analysis happening at that point in order to inform the latter cases? And that, I think, was one of the recommendations from that report.

The oncologist who was on the panel for that report, or for that study, had a meeting with us on Zoom -- because of COVID, obviously we couldn't meet him in person -- and he was able to give us a bit more background to [redacted]'s case in particular, and one of the questions that I asked was, "Why was he in a surgical ward to begin with? Why wasn't he in Schiehallion full stop? Because from

Schiehallion inpatient unit, children were taken to surgery and brought back again. When [redacted] got his line put in he was taken to surgery and brought back again. Why did we have to go in via surgery?" And the reason for that is a general, across-the-board, "He was in surgery because they're better at managing wound care." So that's why we were in the surgical unit because that's where their expertise is. But their expertise isn't line infections. That's what Schiehallion do best. And one of the recommendations that he made, perhaps, was that there needs to be better training in line infection management and also, in fact, that the microbiology order who put a block on the line being given in the morning and not being carried out in a timely manner was perhaps a red flare as well, that perhaps the protocol should be that it happens straight away rather than waiting four or five hours.

It was an insight for us into the goings-on behind, if you like, and the fact that [redacted] was one of many. We were shocked that there were so many, really shocked, and I guess that makes me angrier, if I'm allowed to say that. It was easier to rationalise this thinking he was a fluke. But he wasn't a fluke because -- I'm gonna be really blunt now, trigger alert -- not all children will survive cancer treatment, and we went into it knowing that, hoping that he would survive but knowing that he might not. But if this many children are getting sick for causes that could've been avoided, then that's not a flagship unit.

MR DUNCAN: My Lord, I wonder if this might be a convenient moment to have a brief break. Mrs Gough, thanks so much.

A Okay.

THE CHAIR: Okay, take 10 minutes and then come back in and Mr Duncan'll ask you whatever further he wishes to ask.

A Fantastic.

THE CHAIR: But perhaps if Mrs Gough could leave first.

15:06

(Short break)

15:16

THE CHAIR: Mr Duncan.

MR DUNCAN: Mrs Gough, I have only a few further questions for you, but I would want you to understand that this is also your opportunity to say anything else that you want to say. The things I want to ask you about are all under one heading, and that heading is "Impact". First of all, I wondered if you had any reflections on the impacts, as you perceive them, of the problems that you've been describing on, first of all, the staff at the hospital.

A I used a phrase earlier of "battle-weary", and you saw the impact on the staff over the course of those six/eight months where they were just battle-weary. That first move up to 6A, watching them running back and forth trying their best, they were exhausted, and they were working thirteen to the dozen, where they were dealing with the children and doing everything timely, doing the obs, getting medication timely, and then when they weren't doing that, they were off putting something away in a cupboard and finding a home for a new piece of equipment -- where was it going to live in this ward?

There were interactions with, in particular, Angela over the course of that six months where it was, "Here's another bit of paper. Here's another piece of information that I've been asked to tell you." Purely personal opinion: she was getting worn down with it, and these are human beings as well. And while they are all miracle workers, they're human as well, and it must have been hard on them to not know what they could do. They felt-- I think they felt, 'cause it's not for me to say what they felt, that they were letting us down because the ward

wasn't up to Schiehallion standard, and that all the back and forth was-- they were seeing the extra impact it was having on us. They were witnessing the impact it was having on us.

Q Okay. Next, I want to ask you some questions about the impact of these problems on you. Do you have any reflections on that?

A Mm-hmm. Battle-weary -- again, that word -- where we just kept going. It was, "Just keep going. Look for the rainbows. Just keep going." And when [redacted] rang the bell-- For those of you that don't know, when you finish chemotherapy treatment, there's a bell on the ward and there's a little poem like, "Treatment's done-- I ring this bell three times out loud to say my treatment's done, and I'm on my way," and they get to ding, ding, ding the bell. And it's a celebration moment, and it's a moment, having witnessed a few other people doing it, it's a moment of there's a light at the end of the tunnel, that there is positive at the end of this, that some people do make it. And when he rang the bell, my mother-in-law actually said, "So are you planning a party?", and I nearly fell off my chair. "Are you kidding me? Planning a party?" We literally collapsed across the finish line, but it was just, “Right, we're done. Well done, kiddo. We made it, finished your treatment.”

And we were very lucky to be given a week of a caravan holiday in beautiful Lossiemouth by Logan's Fund, named after a wee boy, Logan, who lost the fight at a very young age, and in his memory, the family have set up a beautiful caravan on the beach at Lossiemouth front, and we went away for that week and we just (inaudible) as a family. And they looked after us so much, they were so kind, they were so caring, and there was a high school group doing a project for school where they had to talk about a charity in order to win the charity money -- it’s a scheme that happens in a lot of high schools -- and they had chosen to speak about Logan's Fund, so came to meet us to ask us how important Logan's Fund was. And we were able to tell them that this holiday for us was a reward at the end of treatment for the kids, but it was also such a validation for us as parents that we had made it through, and an opportunity for the children to have time together because we had spent those nine months as two separate families -- the [redacted] team and the girls’ team. And to see the children have time together -- Now, don't get me

wrong, [redacted]’s stamina was still low, he was still relying on a wheelchair at points. Just because he had finished treatment didn't mean he was fully recovered, and photographs that we've got of him on that holiday -- the wee thin, thin face, the cheekbones, and the big, dark eyes, hair so short. And we were lucky enough to go again this summer, back up to the same caravan, and that was -- trigger alert -- that was when you look at the photograph of him this summer compared to two summers ago, he’s twice the boy. He got to really enjoy it this time because last time he was still so unwell, and that, for us, was healing, but it was just the start of it.

And about six weeks later, we went back to Alnwick (?), and that was a mistake because that was a trigger, because that was our summer holiday that we had already booked when we were in Alnwick the first time. “Let's come back here next year. Let's book it and we'll go.” Fortunately, [redacted]'s treatment was finished, and we were able to go, but I had a bit of a collapse on that holiday because it really opened up to me the difference between the stark reality of who we were a year ago and who we are now. And one of the days I woke up with a migraine, which wasn't unusual --

since [redacted]'s treatment, waking up with a migraine wasn't unusual -- and couldn't get out of bed, didn't want to get out of bed. “Just take the kids and go, Cameron. Off you go.” And that, for me, was the start of a bit of a depression, where there were days where getting out of bed was just-- And I did it, forced myself. “Just get up, Colette.” I'd be lying there in the morning just saying, “Just get out of bed. Get out of bed, make the breakfast.” And I was on autopilot. I wasn't engaging with the children. I wasn't being a very good parent to my standards. They were fed, they were watered, they were clean. The basics were covered, but that was it. There wasn't a lot of happiness, there wasn't a lot of smiling, and yet just beaten cancer. We should be joyous. We should be blowing trumpets. And I think at that point, having had the day on holiday where I couldn't get out of bed and my head was just, “Oh,” Cameron said, “You need to go and see someone. You need to go and talk to someone.”

So, on our way home, we stopped at Jak's Den, which is a facility in Livingston, which is named after Jak Trueman, who was a teenage boy who lost his fight at 15 years old, whose dying wish to his mum was, “Set up a charity to help the families, Mum.” Because the care that he received, there were bits missing as well. There was bits missing for them and she is a guardian angel. She has set up this wonderful charity and it's a fantastic space that the children can go and be in and be safe. And the Schiehallion standard of cleanliness and care is there. Everything is clean, everything is kept clean. It is a safe space for immunocompromised children.

And we stopped in there on our way home and I said to her, “Really struggling. Really struggling. I think I need some counselling.” And that was on the Saturday, and on the Wednesday, I had my first appointment with a counsellor. I had counselling for nine months and was able to talk through what was post-traumatic stress. The focus of that was the line infection and the post-surgery weekend, and the fact that I left the room. I had to spend a lot of time talking round that, rationalising all, and it really helped.

And at the same point as starting counselling, I went to my GP and I have been medicating for anxiety since, and had a quick check-in with them at the start of COVID lockdown and said, “How are things going?” And I said, “Now’s not the time to come off antianxiety medication,” which he wholeheartedly agreed with. I think I am feeling much better now and, having gone through this process of talking through my statement with the wonderful witness support team, that's been another cathartic moment for us.

One of the greatest healing tactics that we have had is to pay it forward. Can't pay it back to the people in the charities that have helped us, but we pay it forward. And so, we've done lots of fundraising and lots of charity work, and the children have been involved in that as well, and has been involved in that as well. Much to his great excitement. And we still do regular collections of toys and things for the fairy box in the ward. Fairy box is a magic treasure box that you get to pick something out of if you get a horrible procedure. So, it means that the nurses can give the child something and become their friend again. Like I said, they're in it for the long haul. But that needs to be replenished, and it's people like us that replenish that. And it's the wee bits of that that make the journey easier.

It took me a while to be able to talk about it in counselling. And in fact, this is the most public forum I've ever been in to talk about [redacted]'s experience. We are a very private family, and we haven't shared his story widely. My extended family don't know the full story of the horror of that day, that weekend. The information that I was sharing, knowing that the WhatsApp messages that I was putting on the “[redacted] Group” - because we created a [redacted] Group so that I could send information out without having to deal with questions. And it was just a notice board that I could post on so nobody could respond to me on it, ‘cause I didn't have time to deal with questions at that point. Knowing that I was sending that out and that other people would then copy that and paste it and send it on to share the word, because never was more prayers said for a boy than [redacted]. The word was out that he wasn't well, and the whole family were praying for him.

So, I was very guarded about the information that I put on that to protect [redacted]’s privacy, and also to protect my mum and dad, who are aged and I didn't want them to know the horror of what we were experiencing. We just got on with it and we just kept going. And having the conversation with them post-event and telling them about it was really hard because they don't want to watch me suffering as I was watching [redacted] suffering, ‘cause they’re still Mum and Dad, even though I'm aged as well. I don't know if I'll ever get over it, but by the same token, I don't know if any parent who has lived through a child cancer journey ever gets over it.

But the fact that the elements of it that haunt me are bits that could have been avoided, had the drains worked, and the bits that wore you down over the course of treatment that was, “What ward are we going to now? Where is it next? And what next? What now?” All of those elements, they wear you down over a length of time and that’s taken a long time for me to get past.

I honestly do not know how I would feel if I had to take one of my children in there now. Anne had to go and get her tonsils out. Her adenoids, sorry, to be correct. And that was about 6/8 months after [redacted] finished his treatment. I don't know the exact date; it’ll be in my statement. And that was a surreal experience. First of all, to go in as a normal patient without the Schiehallion umbrella over us. It meant that she didn't get the gold standard treatment on the day surgery ward. She was in the beds in the big bay with all the other children greeting and gurning. And I just cleaned the whole time we were there. “I'm thirsty, Mum.” “Well, here's the bottle of water

that we brought you. I’m not having anything that anybody has given you.” I didn't trust anything that was there, and get her home as quick as we can. Though we couldn't not take her for surgery, but she wasn't immunocompromised. So, that was in the back of my mind: “She'll be fine. She'll be okay.”

But it really has shaken my confidence in the authority, if you like. I am eternally grateful, and it's lovely that our phrase of “Look for the rainbow” and the fact that the rainbow became the NHS symbol through COVID. We liked rainbows before they were cool. Any of the doctors and nurses that worked with us, I am so grateful for everything that they did for us. I really do feel that they were approaching their job with humanity. We were not just patients. We became friends with them and that they did care about us, and they did care about [redacted]. That is a level of expertise within Schiehallion that shouldn't be lost. And unfortunately, it is being lost because of the situation that Schiehallion is in just now.

I dread to think what it's like during COVID, when extra restrictions are in place in the hospital. Dread to think what the ward’s like and what the people that are in isolation are like now, given the impact that COVID has had on the nation. Maybe people are more supportive of them now, are more aware of the things that they need to be supportive of. The fact that once we moved to 6A, and all of these wonderful support charities couldn't get access to us. They just shut the doors and said, “No infection control, nobody's allowed in.”

So, the music therapist that would come in once a week wasn't allowed in anymore. The visitors that would come in to perk you up weren’t allowed in anymore. Some of the charities would come and just visit you in the hospital to sit with your child to let you go and get a cup of tea. That didn't happen anymore. And I don't know if it's happening yet because, of course, COVID would’ve meant restrictions got even tighter. And that support network is actually essential to help a family get through cancer treatment. It's not just an add-on; it has to be there. And the way that the building is set up just now doesn't support it. It’s not a children's ward. They shouldn't still be in there two years down the line. Children should be in a children's ward, where they get access to the children's facilities.

Q Thank you, Mrs Gough. Mrs Gough, I don't have any further questions for you, but before we conclude, is there anything else that you want to say?

A The impact on the wider family. I didn't talk about the impact on the wider family.

Q Yes.

A It's not just [redacted] that went through this. It's not just Cameron and I. My two daughters went through it as well. And the fact that the ward is set up in such a way that it made it difficult to bring them to the hospital. They couldn't come and be in the room with us. There wasn't enough space for them. And so that's meant that for a long time they didn't get to play with their brother. And while we are amazed at how resilient they have been, it's something that we're still working through. Still working through it. And even coming here this weekend, the fact that we're coming to talk about [redacted] again, that can hurt when you're number two child and number one child's getting all the attention. So, it's not just about the immediate family, it's about the extended family as well.

And I suppose at this point, as I'm finishing off, I just want to extend my gratitude and make it a public statement of my gratitude of everybody that helped us. We were carried by so many people, and we stood on the shoulders of the people that have been through it before us, who have witnessed it and have recognised the things that were lacking in the care plan. And all those charities that were put in place because they saw the bits that were lacking, we have had the benefit of. And also, to my close and extended family, who have supported us through all of this and who are still supporting now. The girls are in good hands getting babysat today by Granny and Granddad again. I'm sure they'll be exhausted by the time we get there.

I feel for the people that are going through it now, and I feel an urge to pay it forward to them to do it better for them, because if you take what we had and the experience that we had and add COVID on top of that, then the families that are in the ward now need the most care. They really do because this is probably the hardest thing they'll ever do in their lives. So, the hospital need to do better at serving them. That's all I have to say.

Q Thank you very much, Mrs Gough.

A Thank you.

Q My Lord, I have no further questions and no one has asked me to ask any questions of Ms

Gough.

THE CHAIR: Right. I'm proceeding on the basis there's no applications under Rule 9, and therefore no further questions. Thank you very much, Mrs Gough.

A Thank you.

THE CHAIR: We do this professionally, but it's quite a long day and I appreciate you coming. Thank you.

A Thank you.

15:44

(<u>End of Afternoon Session</u>)