

Scottish Hospitals Inquiry

Witness Statement of

Cameron Gough

WITNESS DETAILS

1. My name is Cameron Gough. I was born on [REDACTED]. I am [REDACTED] years old.
2. I am the father of [REDACTED]. [REDACTED] date of birth is [REDACTED]. He is 10 years old.
3. I live with my wife, Colette, and our [REDACTED] children, [REDACTED], in [REDACTED].
4. I am a [REDACTED].

OVERVIEW

5. My son is [REDACTED]. [REDACTED] was diagnosed with a Wilms tumour in his kidney on 30 July 2018 when he was 7 years old. [REDACTED] was treated in the Royal Hospital for Children ("RHC") and Queen Elizabeth University Hospital ("QEUH") in Glasgow between July 2018 and May 2019 when he finished his treatment. He attended both hospitals as an inpatient and as an outpatient regularly over that year. Following the completion of his treatment, [REDACTED] attends at the hospital for check-ups. First of all it was three monthly, now it is six monthly follow ups where he has a scan just to check that he's okay and that there's nothing come back.
6. [REDACTED] spent time in wards 2A and 2B of the RHC which is also known as the Schiehallion Unit. He also spent time on 3B, 2E, 1A, 3C, PICU and CDU in the

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RHC and also in ward 6A in the QEUH. Colette and I shared and managed the care of [REDACTED] between us, during all of his admissions as an inpatient and as an outpatient. I can speak to the experience [REDACTED] and I had on these wards.

7. There are some specific events I would like to mention. [REDACTED] contracted a serratia marcesens infection, which was a Healthcare Associated Infection most probably contracted in the RHC. Throughout his treatment there were issues with the water supply, ongoing construction works and issues with fungus which impacted on his experience with the hospital. I will come on to talk about these events on more detail.
8. I have provided the Inquiry with a timeline which I prepared along with my wife, Colette Gough. This timeline shows the dates on which [REDACTED] attended hospital and the wards where he was treated. The timeline is attached to this statement at appendix 1 (**CAG/01**) and I confirm that it is accurate to the best of my recollection. The timeline came about because Colette is phenomenally fastidious. During [REDACTED]'s treatment process there was a lot that we needed to be on top of, when you're medicating you need to be organised. The only way we could manage it was to keep a record, particularly when me and Colette were doing handovers at the hospital. Colette instigated the record. So this was what she did. She had a diary and kept all the records: [REDACTED]'s observations, his blood counts which became quite an important thing because if counts were at a specific level, and he's having a temperature spike, this enabled him to get certain meds that he wouldn't have been able to get otherwise. We became quite good at transferring information and Colette kept a repository for all the information, that's the way the timeline was created.

FAMILY BACKGROUND

9. Colette and I live in [REDACTED] with our three children, [REDACTED], [REDACTED] and [REDACTED]. [REDACTED] is our eldest child and he is cracking; a fun wee boy. He is quite academic and

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cerebral. His sisters are more sporty, [REDACTED] is more bookish which was handy when he was in hospital because he spent a lot of time reading during his treatment. He is quite practical and he has an engineer's brain. He is "on it" and he is aware of what happened to him. Now he's healthy and he's happy.

10. Colette and I worked really hard throughout the treatment process to make it as fun for him as possible. I know that it sounds weird to say getting chemo is fun, but you can make it fun. We, like all parents, shielded him as much as we could from it, so he's doing well. You know, fundamentally he's doing well. He is everything and more that we would hope from a boy that has been through what he has been through. He's great.
11. [REDACTED] is our youngest child. She is the third child, feral, lovely and wild. But great fun with it. [REDACTED] is our middle child, she's lovely. She's very physical and active and skis and skates. Throughout this process we were most concerned for [REDACTED] and that is not to underplay [REDACTED]'s emotions; [REDACTED] was quite good at rationalising things. [REDACTED] is binary, [REDACTED]'s analogue that is the only way I can describe the difference between the two. That is our family and they're all doing fine; they're good fun.

SEQUENCE OF EVENTS: EXPERIENCE AT RHC AND QEUH

Diagnosis: July - August 2018

12. It was the 4 July 2018 and we were on holiday in Alnwick. I remember it being a sunny day. [REDACTED] was in the toilet and he shouted us through and said, the toilet's a funny colour. I came through and the urine was bright red. He'd been eating beetroot, so the immediate thought was maybe it was that. The following day, Colette took [REDACTED] to the out of hours service and they gave him antibiotics. The next day blood cultures were taken at the out of hours service to see if doctors could work out what it was. A few days later the out of hours GP

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phoned us back and the culture was clear. The doctor advised us to go and see our own GP when we got home from holiday.

13. On the 13 July [REDACTED] saw our own GP who took a urine sample, prescribed a second set of antibiotics and booked more blood tests for the following Monday. On 16 July bloods were taken, the urine cultures were clear and the following day the blood tests showed anaemia. The GP referred [REDACTED] to the Royal Alexandria Hospital ("RAH") in Paisley for a scan and renal referral. We spent that whole period trying to work out what it was.
14. It was a fairly slow process. A scan was booked for the 30 July 2018. The day before his scan, [REDACTED] bumped his abdomen and he went green; he wasn't well. He was vomiting so it was obvious that he was deteriorating. The run up to the initial scan was really fact finding and general investigations involving blood tests, urine tests, getting the scan and trying to work out what was going on.
15. When we were on holiday, he was tired. He wasn't sufficiently different that we noticed anything at the time initially. If it had been a girl, we would probably have assumed it was a UTI. That was what we were thinking. Whilst UTIs are not a fun thing for anyone and can be quite debilitating, we weren't looking for anything more than that at this time. There were no obvious swellings, he didn't feel anything or lumps or bumps.
16. In the days leading up to [REDACTED]'s admission I had ripped out the bathroom at home. Colette and the kids had gone to stay at my mother and father-in-laws, because I had ripped out the bathroom. On the day that [REDACTED] had his scan, the girls were at a dance class. Colette and I met at the RAH for [REDACTED]'s scan.
17. On 30 July 2018 we took [REDACTED] to the RAH for his ultrasound scan and all hell broke loose for want of a better phrase. Everything flipped at that point. There was a wee bit of toing and froing of whether it was a high priority or not. I

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spoke to post event who said that he really had to push it to get the scan through because it wasn't presenting itself as a major concern.

18. The scan at the RAH revealed that there was a mass on [REDACTED]'s kidney and he was referred to oncology at the RHC in Glasgow. Colette and I travelled with to the RHC and attended at the A&E department. The doctor in the A&E department was up front about [REDACTED]'s diagnosis. He told us that he was not beating round the bush, and that it was looking like cancer we were dealing with. We went through the Clinical Decisions Unit ("CDU") and [REDACTED] was admitted to Ward 2A in the RHC.

Admission to ward 2A RHC – the Schiehallion Unit: August 2018

[REDACTED]'s treatment plan

19. When we arrived in ward 2A [REDACTED] was admitted as an in-patient to room 10. We met Dr Ronghe who was [REDACTED]'s consultant. An MRI was carried out and Doctor Ronghe confirmed that [REDACTED] had a Kidney tumour; a Wilms tumour measuring around 12cm x 8cm x 8cm.
20. Colette stayed with [REDACTED] that first night. I went home that night to install the bathroom, just to make it work. It was a low priority now. The following day I came back in to the hospital for the next three or four weeks. The girls stayed with their grandparents. Colette and I stayed with [REDACTED], tag-teaming. Generally, there was only ever one of us staying overnight, apart from one of the nights near to the beginning of his admission where we both stayed over. Generally the staff didn't want multiple parents staying in, they were still small bedrooms and it's not a huge hotel room. The bedrooms were well set up though.
21. On the 31 July 2018 [REDACTED] had a CT scan and an x-ray which confirmed the tumour was contained in the kidney. The plan was to start chemotherapy.

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22. On the 1 August 2018, ██████ underwent surgery to fit the Hickman line. Once they knew what the treatment plan was, the staff didn't hang around.
23. ██████'s Hickman line was fitted via surgery under a general anaesthetic. It was fitted to his left side and ██████ called it his "wiggly". The Hickman line was used to administer medication and draw blood. Given the nature of the medications ██████ required, they had to be administered into a vein. The Hickman offered quick access to the vein. The nice thing about the Hickman was because the piping of the line was outside the body, it was a much easier piece of kit for staff to use and it worked well. I think ██████ had a wee green cap on the end of his Hickman line which was to prevent nasties getting in to the line. If I remember rightly, the green caps were sterile and they might have been a barrier as well, but I could be wrong.
24. Underneath the skin there's a wee bend in the line just so it can't be pulled out too easily. I could be wrong but I'm sure that there was a wee tuck in the line and it was stitched in. The dangly bit of the line was taped up out the way. My concern was that ██████, our youngest, would just come and pull it. The line was kept taped up and it was kept clean.
25. Generally the staff didn't use cannulas in Schiehallion. They avoid those like the plague with these kids. With a central line you've got a direct line in to the body so it makes sense to use it. Cannulas are not fun and they restrict movement and they bruise, particularly with these kids. All the staff were fully qualified, there were no first year doctors. With these patients being so vulnerable it was protocol that these patients shouldn't be practised on, for example it's difficult to find a vein on them when they are going through treatment. Schiehallion day care staff were great. They could find a vein in a rock.
26. The difference between a Hickman line and a port, is that a port is fitted into the chest, under the skin. To use the port a needle has to be pushed through the

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opening and then the medical staff have to find the entrance to the line under your skin. It was great because it was sealed and it was clean. Sometimes with ports, if staff are not used to using them they can miss the opening and hit parts of the body, for example muscles, with the needle. ██████████ had a port later on in his treatment and I speak about that later on.

27. Throughout the process Dr Ronghe was the first and major point of call. He was the captain of the ship for lack of a better analogy. We had other doctors involved too: James who was one of the junior doctors and there were a few others Catherine, Kate, Anne-Marie. They were all super. All qualified, very capable and competent; they were fantastic.
28. I am not sure what Dr Ronghe's speciality is, however I do know that he has carried out a lot of work on Wilms. His work was getting published and at one point in ██████████'s treatment he referred us to some publications when we were trying to work out what treatment might follow ██████████'s surgery and he was named in these publications. It was clear that he was the expert in the field and we liked that. At the beginning of ██████████'s treatment, he told us not to Google, because Google sucks and we'd just get worried.
29. ██████████'s plan was the European treatment plan, which is to hammer it with chemotherapy for a period of time. In ██████████'s case this was for four weeks in order to shrink the tumour to a state that it becomes removable. The plan was that there would be surgery to take it out, and the tumour would be cut open and examined to see what nasties were inside it. That examination of the tumour would inform the process that followed surgery.
30. On the 2 August 2018, ██████████ started his chemotherapy protocol which included Vincristine and Actinomycin. I think it started off with Vincristine every week, and the Actinomycin and vincristine was every second week. Then the protocol reduced post-surgery to Vincristine in every two weeks in three and

Actinomycin every third week. As I recall his regime was vinc week one, vinc and actin week two, week three off: but I would have to check that though.

31. At the start of treatment we were given a specific protocol which set out the treatment plan and medication that would be prescribed over a number of weeks. The protocol actually changed throughout the period. In ██████████'s case the periods between the chemotherapy stretched as we went along because he would continually have chemo holds when his neutrophils dropped or he developed an infection.

Description of Ward 2A – the Schiehallion Unit

32. Ward 2A in the RHC is part of the Schiehallion Ward. It is an oncology ward for children and I think they care for some transplant patients too. The ward treated kids with a very specific set of medical needs, they were not quite ICU, but they need very particular care. The important fact is that the children on that ward are immunosuppressed. The infrastructure, staffing and protocols on the ward were set up to look after these kids and to address all the issues that are created by having immunosuppressed children.

Infrastructure

33. From an infrastructure point of view Ward 2A was set up to accommodate children who were going to have long stays within hospital. Our family only stayed in the ward for a month and we weren't that long. If your child had leukaemia, you might have spent a much longer period in the ward. To take account of that, Ward 2A had specific areas for the children to go. The younger children had a playroom. There was a room for the teenagers and they also had a specific part of the ward. The ward treated patients up to 18 years old; an 18 year old is somewhat different from a two year old and the teenagers need their own space. These specific areas were set up for immunocompromised kids, the children on chemo who were admitted to the ward.

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34. There were rules and protocols for use of the playroom. Siblings were not allowed into the playroom. It was only the patient, the sick child, who was allowed to use the facility in the Schiehallion ward.
35. On one occasion there was a parent that brought a sibling in and I had to point it out, it was almost self-policing but these rules were established to protect the patients. Fundamentally you didn't want to jeopardise the children, and someone's snotty brother or sister could be a major implication to a kid whose counts are so low.
36. Within the playroom, everything was fastidiously cleaned. Everything was locked away. Everything was issued to the child upon entering the room. There was one occasion where a family who had a less favourable outcome than we had, donated loads of toys. Some of the toys were porous and because that meant they were difficult to clean they could not be used on Ward 2A. Everything needs to be wiped clean and needs to be able to go in to the dishwasher. It was sparkling. You could actually eat your dinner off the floor.
37. The play leaders did the cleaning of the objects themselves. I assume that cleaners were involved cleaning the infrastructure. The play leaders were constantly cleaning up the room; if it was dirty, they cleaned it up. We all did actually. You cleaned and it became second nature within a day or two of being on the ward. It was to prevent infection as part of the infection prevention control protocols.
38. The play leaders used a lot of Baker Ross products in the playroom. Specifically they had wee school packs. Those packs contained three things: three dollies; three colouring ins; three sticky crafts; three activities and similar. The play leaders would take out the school pack, open it, drop it on the table for the kids and throw away the packaging. Once the kids was finished playing they would throw it all away. Everything was either sealed and disposable, or it was able to

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be washed. The playroom didn't have books. I can't remember seeing any books or fabrics.

39. There were no school lessons as such. I do remember meeting a teacher at some stage during the process. I can't remember when. To be honest, it was so reactive. The kids weren't well. What [REDACTED] needed was what the play leaders could offer, and they were very much responsive to his needs at the time. We didn't need to do maths and English. It was low priority. The kids don't need to know how pyramids are built; they just need to get better really.
40. For us and for [REDACTED], the fact that the playroom was a dedicated space where he could just go along was great. It wasn't 24 hours but it was still great. The play leaders had these wee boxes and if the kids were having a bad day, things would appear, activities from them for us to do with [REDACTED]. There was very much a family theme to the activities they gave us.
41. It was good that the teenagers had their own area. I felt so sorry for those kids because, the thought of doing chemo and puberty and all that next to a two year old, you don't want that. It was good the teenagers had their own facility in Ward 2A, and it was a shame that they didn't have that facility in Ward 6A. I would hate to be a 12 year old having to put up with that. It was a really nice set up; there was a tea making machine in their room. We peeked in. We didn't go in because you're not allowed to go in. There was comfy couches and tellies. No adults. It was their space to go and be kids, teenagers. It was lovely actually.
42. In ward 2A we could get a cup of tea. There was a parents' kitchen where you could actually go and get a cup of tea. My goodness, that's a useful thing at three o'clock in the morning. It was also a place where we could go and speak to another parent that was going through a similar thing to us; that didn't really happen in any of the other wards that were outside of 2A.

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43. The parents kitchen was good. You went in, there was a fridge and freezer. Everything that went in to that fridge was labelled, with your name and a date. The staff were really fastidious about cleaning out. There were two microwaves, a kettle and the freezer. Tea was made from bottled water and the dishes had to be washed in the dishwasher; not rinsed under the tap, everything had to be cleaned in the dishwasher. The dishes were not to be washed in the tap water because there had been an issue with the water. We were told this by the domestic staff. There was a big pile of bottled water in there for us to drink. There was a wee table and a comfy chair, which for us was great because during the day there were two of us in. Quite often, if one of us was with [REDACTED], the other one was through getting a cup of tea or chilling and chatting to other parents and that was good. It was good to have that space to go and de-stress, and get a cup of tea and food. The food wasn't provided for the parents or for the carers there, but there were facilities to allow you to cook, heat up and that was really useful. There were cupboards and everything had to be labelled so if you wanted to go and make yourself a bowl of cereal there was the space in cupboards to store stuff like that. Everything was dated and if it wasn't, it was thrown out.

Staff

44. From a staffing point of view Ward 2A was set up to deal with immunocompromised children. The ward had a greater number of nursing staff. They had, from what I understand, a greater number of doctors. There were no first year/second year student doctors amongst the doctors themselves. From our experience the doctors that treated [REDACTED] in Schiehallion had the time served experience and they weren't using our children to practice on. That was a major thing. The Schiehallion kids weren't getting practiced on for anything as they were too weak.
45. They did have an eye on dealing with children that were immunosuppressed, and who had the capability to deteriorate very quickly. Therefore the staff

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reactions to specifics like high temperatures were very different within Schiehallion when compared to other wards in the RHC.

46. For example, when [REDACTED] had a temperature spike it was quite normal for him to rigor and start shaking. His temperature would be constantly monitored and managed with paracetamol. For these kids you can't really do it with ibuprofen. It was incredible to see what the staff achieved and how they managed the situation. The Schiehallion staff were experts at managing temperatures with paracetamol, to the extent of determining whether to give IV rather than an oral because it would work quicker. I remember on one occasion when [REDACTED] had been given IV paracetamol already to manage the temperature the next step was to give him one oral paracetamol. One of the Schiehallion nurses stood and watched the clock counting down the seconds to be certain of the time that the paracetamol ran out so [REDACTED] could get the next dose.
47. The level of care was high. The staff were also very good at being aware of parents and they listened to us. For example, there was one occasion in Schiehallion when a piece of equipment that took a temperature returned a reading and I thought that [REDACTED] was hotter than the reading. I asked the staff to try the other ear, or change the machine. They did and it transpired, when they went in to the other ear with a different machine he was reading a degree hotter.
48. The attitude in Schiehallion is that you know your child better than us and we will work together. While Colette and I didn't have a clue, the staff were very willing to listen to us and listen to our concerns. I wouldn't say it's a team effort because they were doing the hard work but they listened to what we had to say.
49. There was a music person that came round the ward. Once we saw a music person playing a ukulele. There was a clown doctor who came round for the

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kids. There was also the play team that came up to do work with kids particularly in explaining central lines, and they were great.

50. There was a high level of care from staff across the board. The ward also had something called the bad day box, I have maybe got that name wrong but it was something like that. It was a wee treat box where if a child was having a bad day, the staff would appear with something from the box. For example, one of the cleaners called Michelle would often go and get stuff out the box and give it to the child if they were having a bad day. In fact I think she sent her sons out to go buy presents for children, and actually - that's incredible. There was that level of care amongst all of the staff, and there was the understanding that keeping the kids healthy and making them happy made that process a lot easier. Everything was directed to keeping them healthier and all the staff worked together to do that.
51. The treat box had toys in it. Noreen who is on the reception desk in the ward controls the box. She is great. They're all fantastic. All the toys are sealed. When was admitted, he was handed a new box of Lego because they kids didn't get to share. He went to hand it back when he was finished, and they said no it's yours, we can't use it for any other child, so that's yours. If you're going to spend your money on anything, that's a great thing to do because it works. It was exactly what was needed. It demonstrates the protocols in the ward: the fact that everything's sealed, everything's non-transferrable.

Protocols

52. The protocols in Schiehallion were such that they were much more robust than any of the other wards. I have already mentioned the protocols in the playroom and with toys and treats for the kids on the ward. I have also mentioned the staff approach to managing temperatures with paracetamol.

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53. When it came to monitoring and taking observations in Ward 2A, the approach was certainly more robust when compared to other practices on the wards where we stayed in the RHC.
54. The regularity of monitoring depends on the temperature. To be honest, Colette and I tended to monitor it more than anyone else because we were in the room. I can't remember whether temperature obs were two hourly or four hourly. Generally, [REDACTED] was monitored heavily and he always got monitored really heavily when he was spiking a temperature. When his spike subsided and he progressed out the spike, the level of monitoring tended to ease off slightly because he was getting better.
55. To be honest, they needed to put resources where they were necessary. But throughout the process we were also monitoring [REDACTED]. Not that we had any qualms or any issues but I'm just a paranoid father. It was pretty robust.
56. By comparison when [REDACTED] was in the orthopaedics ward in the RHC, there was only three or four obs a day which is nothing. On Ward 2A it was much more regular and that meant the staff were more likely to pick up stuff and see if there were signs of deterioration. Also in 2A, there was a bit of flexibility in how they did obs to limit the impact of it. For example, they worked obs round providing medicine, so they did everything at once. In some other wards staff tended to come in and do obs in the middle of the night then come in 20 minutes later once [REDACTED] had gone to sleep to give him medication. Then come in another half an hour to take another reading. And you just think, why don't you do it all together?

Description of patient bedrooms in Ward 2A RHC

57. There was maybe about 20 regular patient rooms on Ward 2A. There was an older area for teenagers, but we didn't explore that area. Room 10 was about halfway along the corridor.

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58. As you enter the standard patient bedrooms there was a sink on the right. There was a patient bed with various pieces of storage furniture round about. From one of the walls, there was a proper fold down bed from the wall for parents and carers. It was comfy. It was a nice bed. We always had to get the bed up out the way during the day, but there was a space to have two twin beds or two single beds either side. Then there was the en- suite bathroom off there.
59. The en-suite bathroom had a shower, toilet and sink. It was a wet room, so it had a continuous floor from the bathroom out into the bedroom. The flooring ran up the bottom of the walls for a little bit, and then there were wall panels running down on top of it - probably like you would see in the sports centre is the only way I can describe it. All the taps had filters fitted on them.
60. A lot of the rooms had TVs. On ward 2A there was access to electronic equipment as well, such as gaming consoles. These were cleaned and issued to you by staff on the ward. Once [REDACTED] had played with it we would clean it and hand it back to the staff. It was like a library really.
61. The bedrooms were a fairly reasonable size. The building is curved and the ward was situated on one of the curves. That meant that some of the rooms were slightly different depending whether they were on the inside curve or an outside curve.
62. Ward 2A also had a number of VAC room, which are negative pressure patient rooms. These were situated at the back of the ward. You enter the room through a door from the corridor, it took you straight in to a little hallway. There was another set of doors that you had to go into in order to enter the bedroom. At the double doors there was a holding space in between the two sets of doors.
63. Some of the VAC rooms had storage in the back room area. I couldn't tell you whether that was the VAC rooms in the Schiehallion or not. Generally when we

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were in other wards out with 2A, we were in these VAC rooms because we were always in isolation because the other wards didn't have the level of stringent protocols that Schiehallion did. The only way they could keep us there, and keep safe, was just to put us in to isolation and not let us get involved in any of the rest of the ward.

64. I think that the negative pressure meant that the air was always blowing out of the room rather than blowing in to it, so that bugs couldn't swim in the air. Like the water's flowing downhill rather than uphill, for the lack of a better phrase. It is a double doored room because there was higher air pressure within the room and out with so that the air was moved out.
65. We ended up in a VAC room in Ward 2A at one stage, it was when had been discharged and he had a temperature spike. Quite often my impression was it was the sicker kids and the transplant kids who used these rooms in 2A, although I could be wrong about that.

Ward 2A RHC: The "Schiehallion umbrella"

66. For me the idea of the "Schiehallion umbrella" is something that existed in Ward 2A of the RHC. It is a level of care and appropriate awareness of cancer in children. It is knowing exactly what needs to be done and how it should be carried out. It is being aware of the subtle nuances that are created by the specific illness. It is being aware of the implications of being neutropenic and being immunosuppressed, and understanding how quickly things can go wrong for these patients. It is knowing that one minute things are very calm and then the next, it's not. It is understanding that there are specific protocols that need to be followed to maintain good infection prevention control and avoid infections.
67. The level of care that we got at Schiehallion was so much higher. I felt safe. At no point in Schiehallion did I have any concerns about [REDACTED]'s treatment.

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68. When [REDACTED] was first admitted to Ward 2A in early August 2018, there was a bit of an induction. If I remember rightly, it was quite easy. That was a long day or two. We got shown around and it was a bit like first day of school: this is that, this is what you do, clean up after yourself. I'm sure in the playroom they talked about siblings at that point.
69. In terms of the medical processes we were talked through the process by the staff as they went. I don't really remember getting specifics. The medical staff were very good at communicating with us as they went along and involving us in the process.
70. Staff were very good at telling us that we might end up in another ward. They told us that the other wards were not as good as Schiehallion (my phrase, not theirs) and they told us that we had to be on it. The staff were quite good at making us aware. The nurses were great at involving us in it. Effectively, they were warning us that other wards weren't as hot as the Schiehallion ward, and they told us that we had keep an eye on [REDACTED] when we were admitted to another ward. And we did.
71. I don't remember the Schiehallion staff ever saying "they won't do this and they won't do that" and "they will do this and they will do that". It was just the staff informing us what the Schiehallion standard was and telling us that not everyone was up to that. Maybe that sounds a bit braggy, but the Schiehallion staff were the best at their job; in hindsight that was absolutely true. They tailored care to the needs of the patient. You know, if you've got a broken leg, it's very different to having cancer.
72. Funnily enough, some of the better wards we were in dealt with high need patients. The cardio ward was great, they deal with kids that are about to have heart attacks. They were used to dealing with children that went from being very healthy to not very healthy in a short time period. Dealing with cancer and dealing with a bad heart, it's not far off the same thing; both deal with critical

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children. If you've got a broken leg, it's not fun but you hope the patient wouldn't deteriorate significantly in half an hour.

73. In terms of administering medication, it was completely tailored to [REDACTED]'s needs. Therefore, if he needed paracetamol he got it when he needed it. Rather than say he should get paracetamol every four hours, the Schiehallion staff might say, "well he's okay, we could push it for an hour", or they stood outside the door counting down the seconds and he was given it bang on four hours.
74. The protocols for chemotherapy were established. Medication could only be administered by Schiehallion staff and in the Schiehallion Unit in wards 2A or 2B. There are very strict protocols and procedures as much from a health and safety point of view because these chemicals are nasty things. The staff wear plastic aprons and full gloves because if you get it on your skin it burns you, which is a bit scary.
75. In Schiehallion, doses are bang on. Everything they provided was with two people who check the doses. Quite often [REDACTED] got chemo in day care in Ward 2B and that was an art in itself. There's an awful lot of training to do before the staff can administer chemotherapy. There were Schiehallion nurses in ward 2A that were training to go to day care because it was a different set of skills. Although they could give chemo in ward 2A, generally it was in day care where they did chemo.
76. When it came to the practice of finding ports the day care staff were good at it because they did it on a regular basis. The staff in wards 2A and 2B understood each other's good points and tended to play to their strengths.
77. With regards to other medicines they might need, again it was dependent on the child. [REDACTED] had anti-sickness, ondansetron; that type of thing was prescribed by the doctor and given as needed, but there was flexibility. He was also given an additional metoclopramide to overlap with it. Generally ibuprofen

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was just a no-no because of the low blood counts in these kids, but if it was needed to control a temperature there was a discussion whether it was okay depending if bloods had been taken. That is one of the reasons why we kept such fastidious notes. When we went in to another ward, the standard approach was “don’t give them ibuprofen”, but if your kid’s spiking and you’ve only got four hits of paracetamol that you can give every four hours that’s only 16 hours out of 24 hours, so you’re looking for something to fill in the gap. Ibuprofen was a great overlap with paracetamol so you’re stretching out the dosing because if was spiking for a day and a half, you don’t what to have burned all the meds in the first 16 hours.

78. That is the level of conversation we had with staff at Schiehallion. Whereas there wasn’t that level in the other wards. The staff on the other wards were quite good at listening to us and as long as we worked together, that was fine. I suppose that was the bit about me and Colette learning and taking that information on board, as we became very good at. We were not trying to tell the staff on other wards how to do their job because at the end of the day, they know what they’re doing. But Colette and I became very versed at keeping to the general principles and then tweaking them for our child, and I think that’s what Schiehallion were trying to instil in us as parents. Staff told us the important things over and over again.
79. In ward 2A we had been told to drink bottled water and we were told not to drink from the tap. We were told not to brush our teeth using tap water but to use bottled water. I can't remember the specific time when someone said at the start, but I'm sure we were told only use bottled water in the kettle and just drink bottled water.
80. When Schiehallion moved to ward 6A, while the staff continued to provide excellent care, the infrastructure impacted on the level of care that we received. The ward was smaller and did not have the facilities that Schiehallion had. That’s just the way it was. After Ward 2A and 2B closed and the children were moved

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to ward 6A QEUH, what had been two wards were then pushed in to one ward. It was a smaller ward anyway and they also added in day care, so it dramatically reduced the size of the ward itself.

81. The issue with the “Schiehallion umbrella” was not just with the new Schiehallion ward on 6A. [REDACTED] was often admitted to other wards in the RHC due to a shortage of bed space. As I will come onto, [REDACTED] was admitted with a temperature spike at the end of November/beginning of December 2018. Before we went in, the conversation between Colette and I was, “I really hope we don’t end up in hospital for Christmas”. After the experience in the ortho ward, it was, “you know what, being in hospital for Christmas is fine, as long as we end up in Schiehallion.” That illustrated our level of concern and the differences in the care between the wards. The Schiehallion umbrella did not follow us when we were out with ward 2A.
82. We went from “we don’t want to be in for Christmas”, to “Schiehallion’s great, we don’t mind being in there, just not anywhere else”. It’s sad that it got to that stage.

Discharge and Chemotherapy continues: August 2018 – September 2018

83. [REDACTED] was discharged from ward 2A on the 8 August 2018. The plan was that he would continue to receive his chemotherapy in Ward 2B of the RHC which is the daycare ward in the Schiehallion Unit.
84. On 10 August [REDACTED] had a temperature spike and was readmitted to ward 2A and Room 10. When [REDACTED] had a temperature spike a certain procedure and protocol was followed. A temperature of 38 degrees and above is a sign of infection. This is a temperature spike. The huge thing that everyone was worried about was line infections. The procedure is that you call the ward. We then gave him a dose of paracetamol to get his temperature down and we had to get him to hospital. If we couldn’t get him to hospital within half an hour/40 minutes, we had

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to phone an ambulance. When we arrived at the hospital, if it was out of hours would be taken to A&E in the RHC. When we arrived, they put us in a wee side room because you can't have these kids mixing with any of the diseases and such like. From there he was admitted to whichever ward had a space for him. If this happened during the day, we would go straight to Schiehallion and he was admitted from there to wherever there was a room.

85. Once he was admitted as an in-patient, he was given a few tests, blood draws were taken from the line and then they started him on antibiotics.
86. The treatment was administered and he was treated as if he did have an infection. We had already given him his paracetamol to manage the temperature. The medical staff began taking observations.
87. When he was admitted, Colette and I got into the habit of running through all of 's medication with the doctor on call in the ward. If he went through A&E, we told those doctors everything, right down to advising them that he was prescribed and could take Piriton, just so they knew that it had been approved if anything was required.
88. The blood cultures come back around 48 hours later therefore whatever happened, [REDACTED] was an in-patient for at least 48 hours when he spiked. If we went in on Friday night, he wasn't getting out until at least Sunday morning. In order to be discharged, he had to have a temperature below 38 degrees for 48 hours. If he spiked again then it would reset the clock. Once we got the results of the blood cultures back, if they were clear too, then we could go home after 48 hours.
89. We tended to bounce in and out of Schiehallion during this period. It was a bit of a blur. [REDACTED] tended to spike a temperature quite a lot. In that initial period, when [REDACTED] required to be admitted with a spike, the admissions were all to

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the Schiehallion. We didn't go to any other wards in that period. We bounced in and out, which was fine.

90. After chemo was administered, we would sit with [REDACTED] for an hour to ensure there were no issues or reactions and we took him home. We found that when got a double dose of chemo he was okay. If he got just Vinc, he spiked within about 48 hours and no one could work out why. I had a discussion with the doctors, they thought that the Actinomycin was more likely to cause a spike than Vinc. They thought that the spike was a delayed reaction; that he wasn't spiking 48 hours after Vinc but eight days after Actinomycin. We're not sure. What we did know was that every second week [REDACTED] was going to spike a temperature and we were able to predict it.
91. I always carried a thermometer with me. The in-ear ones could be problematic, so we had a strip called a TempaDOT that is put under the armpit or under the tongue and it's the most accurate of the lot. We carried a handful of those and the in-ear thermometer too. We would monitor the temperature with the in-ear and if in doubt we would throw TempaDOT in and also use it to confirm a spike.
92. In hindsight, I think the reason why he was so spikey was that the tumour itself was dying so it was sending nasty stuff all over his body. He was getting hammered. We definitely saw deterioration in him during that period.

Description of Ward 2B Daycare in the Schiehallion Unit (RHC)

93. Ward 2B in the RHC was part of the Schiehallion Unit. It was the day care facility.
94. Ward 2B was comprised primarily of rooms. As you entered, there was a wee central play area with a waiting area on the left hand side. The reception desk was on the right hand side. There was a long line of rooms in front of you where

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patients got their medicine. It was like a waiting room, or a GP's office. It wasn't set up for long term staying. It was very much, go in, get your meds, get out. If something's serious, the child would be admitted as an in-patient to Ward 2A if there was space or somewhere else.

95. Day care was very much a place where ██████ got an MOT and we found out how he was doing. We saw the doctor and would have a quick chat. Then we saw the nurses who gave ██████ his chemotherapy.
96. In terms of the nursing staff, it is a very different set of nurses between wards 2A and 2B. It was fascinating watching the ward 2B nurses calculate the chemo doses. They used a calculator and worked through the math, it was checked and plotted out.
97. ██████ was okay on chemo. He didn't lose his hair, just a little bit of it. He was nauseous and was given anti-sickness drugs. ██████'s great; you can give him medicine in his sleep, you can just put it in his mouth and he'll take it. We were giving an anti-sickness drug every four hours. Even when he was asleep so he didn't wake up in the morning drug free. He didn't need a feeding tube and kept his weight, which was good. Hats off to him, as it wasn't easy; primarily bribery with electronic equipment helped. He was told that if he put on weight, he got a Nintendo DS. And he did. So you know what, we bought him a DS. In these situations rewards are a wonderful thing. It kept him eating, by hook or by crook, he ate and kept his weight on.
98. Generally he was okay. Looking back at photos now, he looks like crap. He didn't look well. But there were an awful lot of children who suffered an awful lot more. The protocol that he was on was quite a compressed high level of drugs. didn't need many blood transfusions. He tended to get run down and get wee infections, for example got infections on ██████, he got a black tongue. They were infections from being just unwell.

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99. Of course, he spiked every second week. Who can forget going in to hospital every second week with a temperature? Whilst it was scary, because there was always concern that it was something nasty, more often than not it could have been worse.

Admission to Ward 2A RHC – Room 2: 24 August 2018

100. When [REDACTED] was on chemo, he spiked every second weekend. On the 24 August 2018, [REDACTED] had a temperature spike when we were in daycare in ward 2B and he was admitted to Room 2 in Ward 2A. This was one of the VAC rooms and it was the first time we were in a room where we could actually control the heating and air conditioning.

101. The building was hot all the time. The heating just didn't work in ward 2A, or indeed in any of the wards. There was something wrong with the air handling system in there which would explain a lot of the bugs they were having. There was a lot of infrastructural issues in that place. It was very hot and when you're trying to get temperatures down with these kids, it's no good. We were using cold flannels just to try and cool him down. The only rooms where the heating did work were the VAC rooms in ward 2A.

102. During this admission [REDACTED] went in to rigor and that was the first time this happened when he was going through this treatment. Rigor is shaking and shivering. It's a fancy way of describing the state when you get a fever and you get all shivery. It's a shivery fever. One of the daycare nurses called Susan told us that it was not a good sign when chemo kids went into rigor. We were advised to tell the staff if [REDACTED] was rigoring, that we were not to suffer in silence or feel embarrassed about it. It was very affirming to have that support from the staff.

103. [REDACTED] was quite unwell when he was first admitted. It was during this admission that we saw nurse Kat waiting outside the room and counting down

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the time between ██████'s paracetamol doses in order to get the best overlap in his medication. ██████ could only have four doses of paracetamol in 24 hours. That only covers 16 hours so there could be long periods where you are without drugs. The staff had two ways of managing this. They could run a gap of six hours between paracetamol doses, but that means in the last two hours he was drug free. Or they packed the doses up at the front and hoped the paracetamol would take the temperature down. They could administer through IV which also helped.

104. That was the sort of stuff that we picked up from the staff. In addition we picked up cues from ██████. He worked well with hitting him hard at the start of a temperature spike with IV paracetamol. That admission really underlined for us the fact that it was a very precise level of care: nurse Kat was standing outside the door when ██████ was in rigor, she was counting, looking at a clock to when it was time to give ██████ his meds.

105. During that admission on 26 August there was an incident when ██████ used the shower. ██████'s hair was getting long and he was losing his hair, so we decided to cut ██████'s hair and I would cut mine too. The bathroom itself was a wet room. I have drawn a picture on the timeline which is a representation of the bathroom itself.

106. To give you a bit of background, I come from maintenance and worked in water sports, so I have a wee bit of a clue. Generally you would find a wet room floor runs to the drain, and I would expect the floor in a room like that to taper to the drain.

107. I have drawn a diagram to show you the layout of the bathroom. This drawing was done two years afterwards and it is not to scale. The drain was below the shower head, the floor tapered to the drain but only 1 meter square. After this there was a slight ridge, almost like a levee then the floor flattened off. So if

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water landed in the 1m it was ok, but out with this it flooded the room. The purpose of a wet room is it should all taper into the drain.

108. When I cut my hair, the hair didn't drop on the floor and the hair did not block the drains. That was the key thing. The drain wasn't blocked, it was still draining. The easiest way for [REDACTED] and I to do this was to go in to the bathroom, get down to our pants and cut our hair. Once we collected the hair, we had a shower.

109. There was water fairly liberally round about the bathroom, but it was all in the bathroom and a wet room should be designed to cope with this. What we didn't expect was a tidal wave of water to continue on round the bathroom, through the door and into the bedroom. It then ran under the bedroom door and into the corridor in the ward. As soon as this happened, I got in about cleaning it, mopping it up. The cleaning staff were great but we were fairly proactive as well, I cannot remember exactly what was said but there was a comment made by one of the nurses in passing along the lines of, "that's not the only room", or "that's not unusual", or "that is not the only room".

110. What was clear from the comment was that this wasn't an isolated incident. I was most apologetic because I was mortified that I had flooded the bathroom. In response the staff were confirming that it was not the only room that floods, or, that's not the first time it happened.

111. Looking at the design of the bathroom floors, it doesn't surprise me because the moment the water crossed over that slight taper in the floor, the nature of the run was that it run along the back wall, underneath the toilet pan and it ran around and down. Any nasties that were round about the toilet floor run into the bedroom. Following that incident we began to wipe the floor area with wipes and such like. The staff were great for helping us clean up afterwards but there is a structural concern. There is an infrastructural issue where you've got a wet room

where the water doesn't drain downhill. We got to the stage of using old towels to create a dam between the bathroom and the bedroom.

112. The cleaners came in every day. But we made a dam with towels just to catch anything. [REDACTED] wasn't well and we were trying to keep the Hickman line dry, the easiest thing to do to wash him was to get in there with him, take your clothes off and shower together. Two people in that small space, just doesn't work.

113. I can't remember flooding happening to any great extent in any other room but we were on it. We were much more aware of it. That caught us by surprise on this occasion but it didn't catch us by surprise again as we were looking out for it. I can't remember water going out and flooding into the main bedrooms again, but in some of the bathrooms that we stayed in it was not unusual for them to be quite awash. But we just got extra towels that drank it up. We were aware that it could happen so we kept an eye out for it.

114. [REDACTED] was discharged on 27 August and then he attended at daycare on the 30 August for more chemotherapy.

Surgery – admission to ward 3B in the RHC: September 2018

115. On the 3 September 2018, [REDACTED] attended at ward 2B for some blood work and a pre-surgery meeting with the anaesthetist and surgeon, Ms Brindley. He was then admitted as an in-patient to the paediatric surgical ward which is ward 3B in the RHC. The procedure was explained along with potential implications and recovery. The surgeon told us about they were going to access the kidney. They said that they would need to go in through the front. Normally they would go through the back, which is an easier operation. For whatever reason they had to go through the front and it was going to be a long operation

116. There were a few doctors who looked after [REDACTED] during his time in Ward 3B. Miss Brindley performed the kidney removal surgery. Dr Hettle worked with her. Dr Hettle was her right hand person. They were both very good. There were a few trainee surgeons. Mel was another one, he liked Voltron and so did [REDACTED], so they talked about that.
117. Upon admission to ward 3B, the bedroom was not ready. Whilst we were waiting for the bedroom to become ready, Colette and I took [REDACTED] to the playroom. In the playroom there were other children who were not immunocompromised, they were healthy by comparison but some had runny noses and they were snotty. We waited in the playroom until the room was ready. The playroom did not have the same protocols as the one in Schiehallion; siblings were allowed to enter and the toys were not wiped down between uses.
118. Eventually the room was ready and when we went into the room we saw that the bed was covered in red/brown matter. I don't know what it was but it could have been IV contents, blood, poop. It wasn't very nice. We flagged it to the staff and to give them their due, they took it away and gave us a new bed. As soon as the staff went out the room, Colette and I proceeded to clean the room top to bottom. I am not sure if we actually had any cleaning products with us on this visit; we definitely cleaned the room from top to bottom. I think I might have blagged some from the playroom on the ward. Following the experience in ward 3B, that become our own protocol and we cleaned every room from top to bottom when [REDACTED] was admitted.
119. We observed that in ward 3B there were no filters on the taps whereas there were filters on the taps in Schiehallion. The bedroom has a patient bed, a sink and a horrible Z Bed plus an en-suite bathroom. Ward 3B wasn't quite as clean either. We didn't use the play equipment because it was easily accessible to everyone else. Ward 3B also used first year doctors, as good as they were, they were not time served so they didn't have the practical skills that were necessary to work with these kids.

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120. On the 4 September 2018, [REDACTED] underwent surgery to have his kidney removed. Following surgery he was transferred straight to the Paediatric Intensive Care Unit ("PICU"). Parents are not able to stay in the PICU and we were sent home for some sleep. To be honest when your child is in the PICU, there's not much you can do. You just sit and watch and it's very bizarre. It's a very quiet, chilled place and it needs to be. I think that PICU is on the second floor in the RHC, next to ward 2E.

Line infection – Ward 3B RHC: 5 and 6 September 2018

121. During the night [REDACTED] spiked a temperature. The staff suspected a line infection and antibiotics were started. We were at home sleeping so I don't know what his symptoms were beyond that. I can't remember how it was communicated to us, but it was fairly low key. We were so caught up in the cancer treatment and the fact that he had just had major surgery. He was alive and the surgeons didn't have to remove any of his bowel, so for me the line infection was quite low priority at the time and I didn't appreciate the seriousness of it.

122. At some point on 5 September 2018 he was transferred back to ward 3B and as he was considered a high priority, he was put near the nurses desk. However he was not put in a VAC room, he was just placed into a standard patient room: so no vac seal doors, no water filters, year 1 doctors and a different cleaning protocol from oncology rooms. The only real nod to [REDACTED] being an immunosuppressed patient was the fact that he was put close to the front door near the nurse's station.

123. I think at the time that I spoke to one of the doctors on the ward, and he explained that the staff do have a specific skillset in post-surgery. Jenny was the nurse caring for [REDACTED] and she was absolutely fantastic.

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124. In general, ward 3B was just a different type of care when compared to Schiehallion. [REDACTED] really wasn't well. He reacted to the dressing or the cleaning solution that was used round his scar, and he came out in a huge rash. Staff ended up treating it as a burn. Colette and I got to the stage where we were sleeping next to him and holding his arms as he was clawing at the rash. He was started on Piriton but it didn't work so they gave him something stronger which made him feel pretty groggy.
125. At this point [REDACTED] still had his epidural in place, morphine via Patient Controlled Analgesia ("PCA") and he was on antibiotics. I think that the antibiotics that he was on were just for the line infection. There might have been some post-surgical antibiotics as well. But certainly I wasn't aware of any other antibiotics.
126. On the 6 September 2018, [REDACTED] was still an in-patient in ward 3B. At 11:45am two first year doctors came in to get blood from his hands or his feet and blood was drawn from the line in order to do a compare and contrast with the blood in the line. This was to allow them to start antibiotics. Emla cream was put on his hands and feet. Emla numbs the area to allow the doctors to find a vein and draw blood. Generally the doctors hit two places, just in case they can't find a vein and so they've got a backup plan. In these doctors' defences, it wasn't going to be an easy task because [REDACTED] wasn't well but they just slapped on the Emla cream and didn't really pay much attention to his veins. They slapped it on to everywhere on his hands and feet then they went away. Forty minutes later [REDACTED] was very unwell.
127. When the line was accessed [REDACTED] started going in to toxic shock, his heart beat shot through the roof. He was tachycardic which means his heart beats were more than 200bpm. His temperature began to spike, he began to rigor and vomit. Vomiting for [REDACTED] is a sign that he is really not good.

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128. Colette was pressing the buzzer in the room. No one responded. She had to go out to the front desk in the ward for help as there were no staff around.
129. When the first year doctors came back to the room, they began to attempt to draw bloods however they didn't manage to get any out of his hand. This was problematic because without the peripheral draw for comparison, this delayed them getting more antibiotics into him. They were just jaggging him trying to get the blood draw. They continued to try to get the peripheral draw as he was going into toxic shock. They could not get the blood draw from his hands or feet.
130. ██████ wasn't an easy draw but the proper procedures weren't followed and they were just learning. I did say to the nurses afterwards, you can stick needles in all over me, I don't care, do whatever you want, but get someone that has a clue to put these in to my son. Hats off to them, they did go and find someone who could take the draw.
131. ██████ was getting flappy at this point and the doctors continued to try and draw blood without success. Post event ██████ developed an aversion to needles and it was associated with this event. He was great with needles up until this point, but it took a lot of work for him and us to deal with it in the aftermath.
132. ██████ went from being a reasonably happy boy to being very unwell in the space of 40/45 minutes. At this point Dr Hettle came in and he just calmed the room. He was great. He came in, got the draw and basically said, just get antibiotics in. He calmed ██████ down by talking to him about dinosaurs. So the staff banged in antibiotics rather than waiting around for blood test results. Colette had left the room at this point.
133. Jenny the nurse was also in the room. I'm sure she was encouraging the doctors to start a bolus. She was fantastic and also was very much calming the room. As soon as the bolus and antibiotics were started, things began to settle. A bolus is a flush of liquid. Whatever it did, it seemed to do the job.

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134. The big issue there was that we had two junior doctors who didn't have the experience to deal with this escalating situation. It happened over lunchtime and there were no staff on the ward to help. It took a bit of time for people to get on site. It wasn't until Doctor Hettle attended the room that things started moving forward, and it took a bit of time for [REDACTED] to settle down. It was scary. [REDACTED] was panicking as he had a huge toxic shock reaction and his heart rate went through the roof. Colette broke the alarm on the heart rate machine. That experience was a bit of a shift for us. It wasn't great.

135. On the 7 September Doctor Ronghe visited [REDACTED]. The microbiologists had advised that medical staff should place an antibiotic block in the line which cleans it out. This required accessing the line. In discussion with Dr Hettle, I said in a passive way, let's not do this at 4:30pm Friday afternoon when staff are going home. I asked if it could take place earlier in the day and he agreed.

136. At some point, we were told that the infection was serratia marcescens. I can't remember who first told us that the infection was this specific bug. I remember Dr Ronghe told us at some point and we had a meeting with him. Colette and I kept on asking people to tell us the name again, because it's not an easy word to remember. Dr Ronghe definitely told me. Whether he was the first or not, I cannot recall.

137. The problem with this bug, to quote Dr Ronghe, is it's really sticky. It sticks to plastic and it doesn't scrub off easily. From what I understand, the plan was to fill up the line with antibiotic so it's like pouring bleach down the toilet. My concern was when they put in the block that could release a flush of nasties.

Line block – Ward 3B RHC: 7 September 2018

138. It was 4:10pm on the afternoon of Friday 7 September when the antibiotic block was placed in the line and 40 minutes later it all kicked off again. [REDACTED] had

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the same symptoms as before: temperature spike; rigors; vomiting. He received a toxic shower from the line block.

139. Dr Kamal, who was one of the other doctors, attended and started the bolus. He gave ibuprofen to manage the temperature. There was a wee question about whether he should be getting it. Children who are in receipt of chemotherapy would not ordinarily be prescribed ibuprofen. It is related to their blood count, they need to have a certain number before it can be given. I think if he had a blood count of hundred and ten, ibuprofen can be prescribed.
140. ██████ threw up the ibuprofen. Dr Kamal did what was necessary to save 's life and I thank him for that. I suspect the risk of ibuprofen was less than the risk of toxic shock.
141. One of the consultant doctors from A&E arrived who was the head of infection control, because it was now 4:50pm they had issues getting people on site so doctors were called from all over the hospital. Eventually two Schiehallion nurses arrived and I felt sorry for them, because they could hardly breathe as they'd ran from the second floor. The room was full of very intelligent people. Wendy, one of the Schiehallion nurses said that ██████ should not be getting ibuprofen and that he was not to have anymore.
142. I wasn't paying attention to the doctors. I was watching ██████, holding his hand. Every time I looked up there was more doctors. It was five o'clock and they couldn't get people. The staff were just picking up the phone and got anyone they could. The bed was busy when I looked up and there were lots of people coming in and out. But at one point I did look up and go, man, this room is full
143. When she was in the room, the A&E consultant doctor said that the infection that had was a "poo bug", I don't know the doctors name, she had brown curly hair. Colette might know. It was a bit of a surprise and this was the beginning of us

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finding out what the infection was. We didn't know the name of the infection at this point, we did know that it was a line infection though. Dr Ronghe had described it as quite a nasty one to deal with because it was sticky, and it gets in to plastic and hangs on. It wasn't an easy one to deal with and this block was to try and save the line. It didn't work and it took 90 minutes to stabilise [REDACTED]. I looked around the room and saw a sea of scared faces, I clocked Doctor Kamal's face and he wasn't a happy man.

144. It was a bit touch and go and staff considered admitting him to PICU. Dr Hettle had been in the middle of surgery and eventually he arrived in the room. He made a plan then and there to pull the line. He ordered the line as out of bounds and told staff not to touch it.

145. The following day on the 8 September, Doctor Hettle took [REDACTED] into surgery and removed his Hickman line. It was crisis management to be honest, management of two severe crises in two days.

146. It took everyone by surprise how quickly he deteriorated but it was very much an eye opener of how far and fast things could go downhill. That was the thing, I didn't really get to grips with how serious it was until we had a discussion with Doctor Ronghe on the 17 September. I made a glib comment that "it was only a line infection". Doctor Ronghe corrected me and said that the most concerning thing was the line infection, not the kidney, not the cancer, not the chemo.

147. [REDACTED] had two severe reactions but he came through it. He dodged the bullet and that was all that really mattered. On both occasions the inexperience of the room was shown. We were in ward 3B without the full umbrella of Schiehallion care. If we had been on Ward 2A the staff would have been on it and managing that situation within minutes. Now they might not have treated the wound as well as the post-surgical staff, but certainly they would have been all over the line infection.

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148. When it happened the second time around, again the staff dealt with it as well as they could but the timing really wasn't great. They began the procedures on a Friday afternoon and within 40 minutes it had all gone Pete Tong.
149. It was concerning to say the least. I don't know whether the second time was worse or better than the first, because I knew what was happening the second time. During both events, we were at the height of the crisis fear. We were always very aware of [REDACTED]'s mortality throughout this process; one in ten of people with [REDACTED]'s tumour don't make it. We were always working for a positive outcome. I don't want to sound melodramatic but that was the bit where I looked at Colette and thought, we're now in the ten per cent land. This is the crunch point. It was scary. But we got through it and that's all that matters.
150. I would say that in some ways it was easier for me. I think it hit Colette because I was sitting at the head of [REDACTED]'s bed, holding his hand. To give you an indication of how busy the room was there wasn't space for Colette to come and hold her son's hand and that impacted her. Hats off to Colette for taking that bullet, because that's a huge thing for a mother to be able to do, is to stand back. That was shit. That's the only way you can really describe it. It wasn't fun for anyone. We were very aware of [REDACTED]'s mortality, and at point he stared it in the face.
151. I commend the doctors for saving him. I try and rationalise everything, that's been my way of dealing with it all. When [REDACTED] went walked into that hospital with cancer, he had zero per cent survivorship. He was dying. That's it. He was dead. Dead boy walking. The moment the doctors started to intervene, they started to change those percentages. We went from being a hundred per cent in the red to ten per cent in the red. We wanted to keep [REDACTED] in the good figures, not the bad figures. What the doctors did was to keep in that. Colette and I had very little control over that 90 per cent. The 90 per cent is what the medical staff controlled. The ten per cent is bad luck, genetics, all these other influences, and stuff like line infections. This is what concerned me, the other

stuff. If we as parents can affect the odds by even one percent is a difference between one in ten children dying and one in 11 children dying. This is what you think of late at night.

152. That thought process influenced me more when we ran in to issues with rooms and set ups not being good. When ██████ had the line infection, that was a point at which I felt we were in the red rather than the black. We were that ten per cent and there was a risk to his survivorship to say the least. Thankfully, I have been able to compartmentalise it afterwards, because it was a crisis and it was averted. We went back in to the black. Colette had a lot of help, particularly for that event. It was traumatic.
153. Following the line infection and the two incidents, physically ██████ wasn't great. He's quite a robust boy but he was ill. There's no polite way to put it but this time was the only part of the process where I thought, "mm this is touch and go here". When you look up from a bed and see a sea of faces and they're all looking as concerned as you are, that's a bit harrowing. I have a laugh and a giggle about these people being gods and fantastic people, but they are just people. They're doing their job. Until Dr Hettle came in the room, there was a lot of people looking very scared and it was my gauge of how unwell ██████ was. It took him time to get better from this. He did get better and, we got a good result.
154. The other physical impacts is that ██████ had to undergo surgery to have the line removed. I can't say for sure whether the whole episode slowed his recovery down but it must have. I can't compare it with anything because it has never happened to us before. Not only was ██████ dealing with losing a kidney and a reaction to the meds, he was also dealing with a monumental infection and toxic shock and all these other things. You don't just bounce back straight after this. As good as children are, they're not super people but he bounced back faster than I expected to be honest. The line infection really knocked it out of him.

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155. The big difference is between the Schiehallion staff and other staff is being responsive to the particular situation. The fundamental thing here is that in 45 minutes ██████ went from being okay to critical. The primary concern of that stay was this whole episode, it was the crisis point. In Schiehallion they would have been on it in five minutes. I know for a fact they would have been on it quicker. Could they have prevented it from going further? I feel we would have had a much, much faster response in Schiehallion, plus Schiehallion was full of doctors. We always knew that we had two senior nurse practitioners, and had loads of doctors available. The staffing levels are higher in Schiehallion. They wouldn't have been scooting around trying to find doctors or nurses because it was lunchtime or five o'clock. At the other end of the corridor of Ward 2A, you've got the outpatients ward which is full of doctors as well. Within the ward or the ward beside, you could have filled the room with people that knew about line infections and were experts on line infections: that's their concern. For the line infection, the Schiehallion staff would have been much faster at response, whether that would have led to a quicker recovery, I don't know. ██████ was immunocompromised. He was the scary risk area.

156. Don't get me wrong though, Jenny and Dr Hettle were fantastic, and I thank them. But Schiehallion would have been faster because their area of expertise is oncology and line infections.

157. I don't know how long that ██████ was on antibiotics to treat the line infection, but he didn't have them when he was discharged on the 13 September.

Hospital Acquired Infection ("HAI"): 17 September 2018

HAI: Communication

158. On the 17 September 2018, Colette and I attended a meeting in Ward 2B with Dr Ronghe and Dr Inkster. At that meeting the doctors spoke about the Serratia

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Marcesens infection [REDACTED] had contracted. They told us it was hospital acquired. I do remember saying, "you know, it's only an infection". Dr Ronghe wasn't forceful because he's such a wonderfully gentle man, but he made it clear that no actually this infection was the most serious thing. This infection was the most concerning thing of this whole period, not the kidney, not the cancer. No, the infection was the major concern. That was a rocket up my backside and there is no other way to put it.

159. At one point there was a suggestion that it might have come from PICU and that it was possibly from the drains. But I don't know whether it was that meeting or another discussion. Colette will be able to fill in on more of the specifics from that meeting as I can't recall much more than that. For me to move forward, I had to compartmentalise this stuff. The crisis point was done: we've climbed over a hill, let's not get another hill like that again.

160. When we were told that the infection had come from the hospital and it might have come from the drains or from the water, it was a double edged sword just to use another analogy. Some of me was slightly relieved. The moment they said "poo bug", you immediately assume...is this my fault? Did we not clean the bathroom properly? Is this our fault that our son was so seriously ill? Hospitals are clean, we thought that you don't get infections from hospitals. I assumed it must have come from us.

161. I had quite a lot of guilt and I questioned if it came from us. I thought that maybe we needed to up our game. It was a major concern that it was our fault. I know Colette felt the same way as well. We actually discussed it afterwards. In some ways we were quite happy. On the other hand it was a bit sucky, so while it eased our conscience it put an awful lot of pressure on us post-event. We had to be on point every single time we walked in to that hospital.

162. I suppose that's where I would say that it put a bit more pressure on me as I was first line of going in with [REDACTED] when he was admitted with spikes. That was

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where I felt it was on me, I felt I couldn't trust anyone and I couldn't relax at any point.

163. We didn't need the additional level of anxiety of wondering, is this ward going to be okay? Is this going to be clean enough? Are the filters on the taps? I had a mental checklist every time he got admitted which was every second weekend. I was thinking, have I got this? Have I got all the appropriate infrastructure to be able to cope with whatever ward I'm in? When I got into that ward, I needed to be able to make sure that it was clean. But I also need to do it in such a way that I didn't damage the relationship with the staff. Another key thing we found out quickly was that we had to try and establish rapports with the doctors and nursing staff with every ward where [REDACTED] was admitted.

164. This was primarily because if you had a good relationship with the doctors and nurses, it makes your life an awful lot easier to be honest. These people become your family, almost. You don't want to be seen as a pushy parent because having seen pushy parents on wards, the staff tend to perceive them as a difficulty. They become an inconvenience. Whereas if you're a nice parent, people are more likely to be there for you.

165. Every time I walked in to a hospital I had to be able to go in, clean the room, get everything we needed, but do it in such a way that it didn't get the backs up of the nursing staff because we needed to maintain a good working relationship with them.

166. It did create a lot of pressure for me. I suppose that was my kickback. It wasn't so much a crisis, but I found that it wore me down. For me, it was very much a marathon. To summarise, it put a lot of pressure on me to make sure that the hospital did their job properly because they didn't do it the last time when contracted his infection. It was on me.

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167. At that point, in some ways the cancer became superfluous because this infection had been underlined by Doctor Ronghe as being the most concerning thing; not the cancer. For me this was the ten per cent, this was us in the red. The cancer was getting treated. It will either kill him or not. I can't control that. Where we might be able to control some of that ten percent, of course you're not going to sit back. It is not an individual responsibility but actually it created a lot of responsibility on me as a non-trained person.
168. At the meeting on the 17 September when we were told about [REDACTED]'s infection, we were not told a huge amount about the closure of ward 2A at the time. From what I remember, we were told it wasn't going to be for a protracted period of time. I think we expected to be going back to Ward 2A around about Christmas time. I do remember people saying it was not going to be long. Oh how wrong we were.
169. I think that Doctors Ronghe and Inkster told us that the reason for the ward closure was issues with the water system. I can't remember the specifics though. At that point I can't remember if we were told where the children were going to be moved to.
170. I can't remember specifics of any of the hospital staff sitting us down and saying: this is what's going on, and we've got a plan. I don't remember ever seeing a letter saying or an email saying: here's a summary of what's going on, this is where we're going, these are your new protocols, this is how we're going to do it. I don't have a copy of anything like that.
171. I don't remember being sat down specifically having a retraining on the new set up in Ward 6A. I don't remember a formal or specific time where we sat down and we were told, these are the new parameters. It felt like it was an evolving process, and understandably so because it was a make do and mend if we are brutally honest. Ward 2A was gubbed. The solution was a bit Heath Robinson. It felt like the hospital did make it up. They did their best with what they could, but

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the fact that they had to move the kids in to the adult ward was reactive rather than proactive. That is okay, but it was ever evolving.

HAI: Needle aversion - Impact on

172. Following the line infection, ██████ became very needle averse. We had to do a lot of work with him. He's a smart cookie and we can rationalise with him. Thank goodness that we were able to do that, because there was an awful lot of work with him. ██████ and I developed a strategy. This is going to sound brutal but it was a restraint technique. I had a conversation with him about how we would do this. To stop him jumping about all over the place, ██████ would sit across my thighs and I would lock my arms and restrain him. He was lying in a banana shape across my legs. We discussed it and found the position that he was comfortable with.

173. I was restraining him: physically restraining him to have a needle. Thankfully I could rationalise with him but we had to do a fair bit of work with the play team to deal with it. We did lots of stuff, and bribery, games, threw money at it, threw computer stuff at it and did everything we could: carrots. Thankfully it was more carrots than sticks.

174. We discussed it quite a lot and the thing that he goes back to there is the needles and being treated like a pin cushion. It didn't make it easy post event and it made the access to his port something else we had to deal with too. It was the nature of the subdermal where there was a needle going in to the skin and they needed to be bang on. I speak about that later on.

175. We did some work with the play team to help ██████ with his needle aversion. We looked at infrastructure. There was a wee buzzy bee that desensitised him. It's like a holding a sander and it blocks neurons or something like that. We placed the wee buzzy bee upstream of the area where the needle was to be inserted and it desensitised him. ██████ liked the sounds of that and he could

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get with that. There was a lot of work that we had to do and it coincided with his treatment as it progressed.

Treatment plan following surgery: September 2018 to June 2019

176. In ██████'s case, the chemo that he had in the lead up to the surgery killed the cancer completely. Normally what happened is the doctors would remove some live flesh and they could do tests to completely identify what type of cancer it was, and work out whether it was a nasty or not so nasty one. In ██████'s case they couldn't do that because it was dead. At this point Doctor Ronghe told us that ██████ was so unusual. Treatment protocols are developed by creating data, but there's no data existing for ██████'s case as there was no live tumour left. So the question was what do we do next? At this point he told us that there was the opportunity for Colette and I to go and have a read and see what we wanted to do about the final protocol once the kidney was removed. There was a discussion as to whether we should give ██████ chemo if the tumour was dead. If he was a younger child, the recommendation was not to give him chemo because his cancer was stage one. But because ██████ was older, it was a more complicated. Doctor Ronghe kept us completely involved in the process as we looked at options. He referred us to some articles he published.

177. It was a bit up in the air because of ██████'s age. There was not enough background evidence to suggest what the correct course was. There was a fair bit of head scratching, every year around 60/70 kids get this tumour and maybe only one of them is ██████'s age. That could be anything from a stage one to a stage four. If you start doing the math, there's not that many children that are in ██████'s position where the chemo hammers the tumour so effectively.

178. Eventually it was decided that ██████ should undergo chemotherapy post-surgery. As tough as chemo is, it was very much seen as a disinfectant cleaning up of the area rather than treating specific stuff that's still there.

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179. As a result of the infection, I am not sure if there was any delay to ██████'s post-surgery treatment commencing. He was discharged on the 13 September and within a week he was back getting chemo treatment. The line infection might have delayed the next stage because he didn't have a line in following the infection. He began post-surgical chemo on the 20 September, and Colette and I had to pin him down so that two nurses could get a cannula in. That was hellish but it was necessary to get on with it.

180. Similarly when ██████ had a chemo spike on the 21 September and he was admitted to Ward 2A. Staff worked through the protocol and antibiotics were given via cannula. When ██████ spiked, generally his chemo continued as the spike was considered to be a reaction to the chemo

Port fitted – Ward 1A RHC: 26 September 2018

181. On the 26 September ██████ underwent surgery in ward 1A in the RHC in order to have a port fitted. Colette took ██████ in for that surgery.

182. A port is a valve that sits under the skin. There's a wiggly line attached and that's all below the skin. To access the port, staff stick the needle through the badge. The needle sticks in through the port and it has a cable on it, they strap that to him. There's a way of docking the needle in using a gripper, so it is in your body. The advantage is the port can be sealed up between uses, so you're less likely to get an infection. However to use it staff need to hit the needle in the right place, therefore it's a bit more of a faff to access the line, and it needs to be accessed the correct way. If you don't get the gripper needle in at the correct angle you hit muscle and not the line.

183. ██████'s port was up on his chest on his left side. The port moves around a bit, because it sits underneath the skin. When Schiehallion staff accessed his port they had him lie in a particular way. There was a very specific angle to go in

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at, and the great thing about the Schiehallion day care nurses is that they knew exactly how to get him in to that position and get it right. They instructed us when accessing his port.

184. Whereas we found that if [REDACTED] was being cared for by people who were trained but not an expert, they quite often missed the access with the needle. This meant the needle was going in to the muscle. With [REDACTED] you always knew whether they hit it first time: if he yelled, they missed. If he didn't make a sound, they were fine.

Transfer to Ward 6A QEUH: 26 September 2018

185. Following his surgery to have a port fitted, [REDACTED] was transferred to Ward 6A in the QEUH as the Schiehallion Unit in the RHC was closed and the ward had been decanted to the adult hospital. Colette was with [REDACTED] for that admission and she will be in a better position to provide details about that particular experience. [REDACTED] was discharged on the 27 September 2018.

186. Throughout October 2018 and into the start of November 2018 [REDACTED] was in and out of Ward 6A for day care appointments, to receive chemotherapy and also for a few in-patient admissions when he spiked a temperature following his chemotherapy treatment. We rode with it, but the facilities in Ward 6A were not great.

DESCRIPTION OF WARD 6A QEUH

Infrastructure

187. Ward 6A was an adult ward. I think it was geriatrics. I could be wrong but geriatrics were next door. The ward was set up for adults so you had a standard sized room with a standard sized bed which was great because we ended up having to sleep with [REDACTED] a lot of the time. The bathrooms were smaller

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rooms but they were square in shape. That was one advantage rather than some of the wedge shaped rooms that existed in ward 2A. However, in terms of the infrastructure in ward 6A, they didn't have as much storage space as ward 2A. There were wee plastic storage tubs in the toilet as there was less storage for the parents in Ward 6A.

188. When we went into ward 2A, we had space in the bedrooms to spread out because we were doing long term. The rooms in ward 6A were weird rooms. They had a fold down Z-bed rather than the wall bed for parents and carers. I don't think they were any VAC rooms in 6A. The kids were pretty much always in isolation in their bedrooms, this was infrastructural isolation as there was nowhere to go. There were no facilities for parents. There was no play facility. There were no VAC rooms in ward 6A and anyone who needed a VAC room was down on floor 4.

189. The ward itself was split in half so the top end became the old 2A for in-patients. The other end of the ward became day care which was the old Ward 2B. A small waiting area for day care patients was created. The patient rooms were adapted at that end by removing some furniture to give space and allow chemo to be administered.

190. The infrastructure was set up for geriatrics, not for kids. Certainly not for kids who are staying long term and who are immunocompromised. There was no play room. Staff ended up putting a couple of tables in the corridor but that gave rise to issues related to infection control which wasn't great.

191. We didn't encourage our kids to go and play in the corridors. Patients and families were much more isolated because there was no focal point for you to actually go and chat with anyone. There was no area for a parent kitchen.

192. In ward 2A, Schiehallion was very much based around the nursing station. The playroom was straight across from the nurses' station so everything was there

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and the nurses were on hand to make sure you're safe. While there was a small station in ward 6A, it did not act as a focal point.

193. There was a dramatic reduction in bed spaces in ward 6A. This wasn't great either. Which is why there was no playroom for kids and common room for the teenagers, because at the end of the day the attitude is it's more important to fill the beds rather than to have space for play. There were no areas for the play staff.

194. It was just a hospital ward. The staff did as well as they could. The key thing was it led to a more isolating experience. The fact that there were fewer rooms and the fact that the day care was integrated into the same ward opened up issues about people traipsing through the in-patient ward. There was some control but the parameters for day care access is different from the parameters of Ward 2A. It is like walking through ICU to get to A&E.

Staff

195. The ward itself was full of Schiehallion nurses and doctors so in that respect, it was absolutely fantastic. The cleaning staff and the cleaning regime was as it had been previously in Ward 2A, so we still had the same people round about us. We still had the umbrella of the Schiehallion people which was a great thing.

Protocols

196. The treatment was the same, from what I understood. The protocols were established, for example if you have a temperature, you will be treated in same ways. The procedures for observation and medication remained the same as in ward 2A and we had the umbrella of the Schiehallion protocols. The level of care was fantastic.

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Impact of the move from ward 2A RHC to ward 6A QEUH

197. Following the move from Ward 2A, we had the partial umbrella of the Schiehallion staff and protocols but Ward 6A did not have the infrastructure and that made everything harder.

On the staff

198. I don't know how the nurses and doctors did it because they must have felt the strain. In some ways it was a shared battle that we all went through. Colette and I really felt for them, but the level of care didn't diminish. The staff worked their socks off to be able to be as professional as they could be under their new surroundings. But it was a different environment, so it must have been difficult.

199. The move to ward 6A must have been very difficult for the nursing staff. It is a credit to the staff that the impact of this didn't come across with their working practices because their morale must have been shot to heck, particularly coping with all this additional stress. They didn't say much, but you got the odd wee comment and nothing specific, but it must have been hard. They did so well to cope with such difficult surroundings. The staff didn't have the infrastructure on Ward 6A and that must have made their life hard. I am complaining about not having a kettle. The staff didn't have adequate storage facilities in the ward and the infrastructure around about them to allow them to do their jobs. It must have been really, really difficult for them.

200. I am surprised it didn't impact more on them. It's a credit to them that it didn't impact on them more. In particular the nursing staff would try and keep us as up to date as they could but it was such a moving thing. There was never a formalised thing where we were told "this is what's going on". I don't remember a formalised approach. Again as this was so changeable, it was not an easy task for them and I do not envy them.

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201. The staff were having to cope with other stuff on top of that. There wasn't a parents' room, so we had to press the buzzer in the room to get a drink of water. This is stuff that they shouldn't be bothered by, but they were being bothered with it because the infrastructure was not there. There was much more focus on patient management rather than patient treatment, because the infrastructure wasn't there.

202. As there wasn't a parents' room, anytime you wanted anything like water or a cup of tea, the medical staff would go and do it. But that meant that they had to leave treatment to go and make you a cup of tea. It increased their workload. I was reluctant to do it, but I did occasionally. Although I did work out where pretty much every hot tap was in the whole hospital and we became pretty good at it. It was like Raiders of the Lost Ark to get a cup of tea. The staff had to deal with additional workload that wasn't there in Ward 2A.

203. We were quite unusual because when [REDACTED] spiked he tended to spike over the weekend and we didn't really see any of the play team when he was admitted to Ward 6A. Whether they were available midweek, I couldn't really tell you, but we certainly didn't have access to them. The staff might have been there mid-week but I don't know how they could have done their job as there was nowhere for them to do it. They must have either gone and done it on a room by room basis which is a nightmare, or they were just not being able to do their job at all. I did see them once and one of the play leaders mentioned that their storage was over the other end of the hospital. If they needed anything, they had to get the lifts out which is a nightmare because they took so long or they took the stairs, six flights of stairs. They then had to walk over to the RHC, get the stuff and walk back to the QEUH. One of them had a pedometer, I forget the numbers they were talking about, but it was thousands and thousands of steps to be able to do their job because they didn't have a storage area in ward 6A.

204. While we didn't have access to them, I think they will have been trying to provide the service but it would have been dramatically impacted.

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Impact on witness

205. We stopped meeting other parents when we were on ward 6A. I was so glad that [REDACTED] received his diagnosis when he did, while we were on ward 2A, because at least we had the chance to meet some parents before the move and we had some support. I remember going in to ward 6A to pick up meds one night and I met guy in the lift. We started chatting we spent two hours just gassing. The ward environments tend to be quite female heavy, it tends to be filled with mums rather than dads. That's just the way it is. I think I was the first guy that he'd had an opportunity to shoot the breeze with since his child was diagnosed. It is good to speak to people who are going through the same as you as they get it. Afterwards I thought, my goodness, I am glad I'm not in that situation where you don't have the people for the support. At least we had support at the start.
206. I really felt sorry for the parents who began their journey in ward 6A. They would likely have all the scared emotions, they'd be dealing with all the issues of chemo. In ward 6A it felt like there was no one to speak to who had gone through it and walked in your shoes because everyone is trapped in their rooms. That is tough and it can't have been easy for them; not easy for them at all.
207. The nature of the infrastructure in Ward 6A was though that even if you weren't in isolation, you kind of were because there was nowhere to go that was safe for the children. It was infrastructural isolation rather than a prescribed isolation in a properly fitted out room. There was nowhere for us to go. There was nowhere for us meet up, and you can't go in to other people's rooms. It's not as if you could even go and chap on the door go in to their bedroom.
208. In ward 6A we got meals with the children. Although the food wasn't great, I'm not going to complain as they gave us free food. We were very limited to those meals and the nature of having a chemo kid is their appetite reduces so the key

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thing is to get food in to them I found we never actually ate our dinner at the time we would normally eat dinner. It could take a while to get food into [REDACTED] if he was feeling unwell. By that point the hospital food had turned a bit rubbery. In ward 2A, we would just go and make something in the kitchen. There was no facility in 6A, so the options were you could go over to one of the other wards in the children's hospital which meant leaving your sick child, or you survived on chocolate and crisps. As a result we carried a lot of food with us and ate an awful lot of sweets and chocolate. It was necessary. Whereas in ward 2A, we brought stuff, microwaved it and it worked really well. You could at least try and eat healthily. More importantly you had the ability to heat food for your child if the hospital food wasn't working.

Impact on

209. [REDACTED] became very isolated in Ward 6A. He wasn't socialising with people of his own age, and he wasn't socialising with people who were going through the same experience as him. One of the good things about Ward 2A was that while the kids didn't really talk about treatment, he was in the same space as the other patients so there was a shared experience, a shared bond: there's a normalisation. If you're in a room full of five kids and they've all got shaven heads and feeding tubes in, it makes them normal. Actually [REDACTED] not having a bald head was unusual.

210. If the children don't have that experience, then it removes that area of normalisation and removes the opportunity to just play. There was no opportunity for that in ward 6A. When you're with other cancer kids you become just a normal child. [REDACTED] was always a cancer kid with everyone else and he didn't have the opportunity to be just a normal kid, because he didn't have his peers round about him. He did cope with it very well but he ended up socialising very much with adults. I wouldn't say he lost his childhood, because Colette and I worked hard to mitigate that, but in ward 6A there wasn't an opportunity for him to play as much as he could when in Ward 2A.

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211. We worked at it but we're very lucky that [REDACTED] was so cerebral because we did lots of books and reading. His Grandad brought in wee Warhammer soldiers and he enjoyed painting them. It was all very geeky, for lack of a better phrase. There was no socialising. He became a grown up geek rather than a wee boy. At seven, he shouldn't have been doing activities for a 13 year old. I did expect that he would get into these things eventually, but not at the ages of 7/8 years old.

Communication: Move from Ward 2A RHC to Ward 6A QEUH

212. I feel that the hospital management did not really have a clear plan and they didn't really communicate anything about the move to ward 6A. Hindsight's a wonderful thing. I understand that the move to ward 6A was a reactive rather than proactive response. No one planned for this to happen. No one wanted this to happen. To a certain extent, I would suspect the hospital management were having to roll with it. Therefore, they couldn't have given us say, a six-month strategy, because no one knew what the strategy was. I think a lot of parents were rolling with the punches. For us, as long as [REDACTED] was getting better, we'd get around it.

213. In that respect there's only so much you can expect to happen. I think in any one of these situations you always wish there was more information and maybe more formalised communication with us as parents. With hindsight the hospital should have been clear at the start what the issues were and how it was going to impact the patients. If they knew the decant to 6A was going to be long term, then they should have told us what their strategy was. They should have highlighted any problems and told us how they were going to deal with the problems.

214. To develop a strategy like that would have taken a fair bit of resource that maybe they didn't feel were necessary at the start, because they hoped it was only

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going to be a fairly short period. However as time progressed, it would have been useful to have had a more concise and robust strategy for how they were going to deal with it. I can accept the sticking plaster at the start in September 2018, but after Christmas 2018 which was the first deadline then the hospital management really needed to have a plan B.

215. I'm a planner. I would have had a plan B at the start, if it were me. Maybe I wouldn't have had time in that situation because I was dealing with implementing plan A, and it's more important that they dealt with plan A than producing plan B. However, having more information would have been much easier for everyone involved and they should have been transparent and highlighted any issues with their strategy issues and delivering the strategy.

Temperature spike Ward 2E RHC – Cardiology ward: 13 November 2018

216. On the 13 November 2018, ██████████ spiked a temperature and he was admitted as an in-patient to Ward 2E in the RHC which is cardiology. There was no bed space in Ward 6A, and this meant that ██████████ had to be accommodated out with the Schiehallion. There were fewer beds in the ward when Ward 2A closed and moved to Ward 6A.

217. We found that because the number of beds in ward 6A had reduced, the kids with A.L.L. (Acute Lymphoblastic Leukaemia) tended to go in and stay in for longer periods. Beds would very quickly get tied up with A.L.L kids. There was very little capacity to cope with the ██████████s of the world.

218. ██████████'s temperature spike in the cardio ward was an easy spike. Some are more difficult than others. The cardiology medical staff were absolutely fantastic. The ward was nice and it had a parents room as well. It was a lottery as to where you would end up though.

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219. When [REDACTED] was admitted to other wards, the full Schiehallion umbrella didn't travel with him. He didn't have the Schiehallion staff, he was cared for by the staff that worked on the ward where he was admitted.

220. The established protocols for treatment travelled with him. When he was admitted for a temperature spike, he was given his antibiotics as usual. Blood cultures were taken.

221. The key thing was there wasn't a Schiehallion nurse on the ward with us and there wasn't an expert available who dealt with his things. I would say that some wards had a greater level of expertise and we felt more comfortable in those wards. In the cardio ward, we felt like these were the top dollar. And whilst they weren't experts on chemo, I had confidence in them.

222. With regards to the actual travelling, we were just put into isolation in these other wards. This was because the other wards did not follow the same general protocols as 6A, the common spaces would not be safe for [REDACTED]. That was us, we were in our own wee world on other wards. We were treated like a separate entity. [REDACTED] still got the meds. But the level of care was different in other wards.

The crash bag

223. We kept a crash bag in the car at all times in the event that [REDACTED] required to go to hospital. The crash bag was a wheelie bag which had thermometer, and a spare thermometer as one time we ran out of batteries, so we needed to carry a spare. We also carried paracetamol. Generally we kept all the drugs together as a centralised thing that we'd grab and take with us and we'd just hand them over when we got to hospital so they could start treating him straight away.

224. We also carried changes of clothes, toys to keep [REDACTED] amused, cleaning products, food and water. We always carried bottled water because we didn't

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know how easily we would get it on other wards. Food because we didn't know whether we would get food or not. Lots of chocolate and sweets just to get you through the night. Wallet and phone. The crash bag stayed in the car the whole time.

225. We also carried a travel kettle and flasks at three o'clock in the morning and you hadn't eaten or drank all day, there was maybe no hot water facility nearby and was unwell it was good to have some way to get a cup of tea. We learned where the hot water points were, for example beside PICU there was a really good parents' room. So you could come down, fill up your flasks and you had your flasks for through the night.

226. This sounds really sad but Colette and I got to the stage where we published a guide on Facebook for all the parents saying, if you end up in this ward, this is what you need to take. If you end up in that ward, this is what you need to take. You never knew which ward you would end up in.

227. I also had a separate rucksack. My rucksack had a change of clothes, a thermometer and a bottle of water and paracetamol. If we got caught out anywhere, I could go straight to the hospital. I always carried that rucksack with me.

228. Given the amount of stuff we had, that was why I tended to be the first one in, just to physically manhandle all the stuff that was needed. Most of what was in the bag was toys and cleaning stuff. The reason we carried so many cleaning products was a protocol we implemented ourselves which was born of experience on other wards. Having seen the dirty room in Ward 3B, and having [REDACTED] getting a line infection in that ward: it was not acceptable. Generally cleanliness was okay but the level of cleaning in Schiehallion was so much higher and we couldn't take the risk, especially when we didn't know where we would end up.

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229. When [REDACTED] was admitted, the first thing I would do is get [REDACTED] to sit on the bed and I would go round and clean the room top to bottom and clean the bathroom. Normally it didn't look like it needed it, but we didn't want [REDACTED] to contract another hospital acquired line infection, and we would tell people we were doing it. Even if the surfaces were clean, I cleaned under the tables inside the drawers, all the handles and toilets.

230. I didn't have concerns about the level of cleaning in Schiehallion: we had confidence in Schiehallion. Certainly visually, Schiehallion always looked considerably cleaner than every other ward because they had two or three cleaners doing one ward as opposed to one cleaner doing two wards. By the law of averages it's going to be getting done better. We also didn't find stuff lying around in Schiehallion. In other wards you would open up drawers and find things left in them. I found a pair of women's underwear in a drawer in one of the wards we were in, it wasn't Schiehallion but I don't recall what ward it was.

Admission – Orthopaedic Ward 3C RHC: 7 December 2018

231. On the 7 December 2018 [REDACTED] was admitted to Ward 3C of the RHC with a temperature spike. Ward 3C is the paediatric orthopaedic ward. There was no bed space in Ward 6A. He was admitted via A&E.

232. The A&E staff struggled to get the line in his port and immediately this flagged up concerns for me. While it was never explained, if you can't get the line you begin to question if there is a problem with the line, is this a line infection we're dealing with here? After 5 failed attempts, staff couldn't access the port and that was concerning. [REDACTED] was spiralling and becoming more distressed.

233. Eventually one of the doctors said, stick in a cannula. I questioned them and asked, can you get this? Are you actually going to manage that? The doctor in charge assured me that he would get the cannula in and he did. They were able to start antibiotics. This event occurred in A & E.

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234. In Ortho I tried to keep the mood chatty and light. Colette and I did not want to be perceived as pushy parents, we really made an effort. We always make an effort to be as accommodating to the nurses as possible. We tried to remember that they might be having a crap day as well. Generally we erred on the side of cutting them some slack.

235. The key thing was they couldn't get the line in, so I was already at a heightened state of concern. We received very poor care in the ortho ward. The staff were not regularly monitoring [REDACTED]. I counted three observations in one day. If a child has a line infection, they should be getting monitored more than three or four times a day. As we know, last time he spiked he went from okay to not in 45 minutes. That was another key concern for me.

236. We also had issues about actually getting medication at the appropriate times. It is important that medication arrives at the right time. Medication when you're spiking has to be reactive so the timing has to be flexible. If [REDACTED] needs paracetamol, he needs paracetamol at that point. The staff weren't on ball reacting to this. I had to go out to the nurses station two or three times to say, "he's spiking, you need to come and see him, he needs some meds". [REDACTED] was spiking, he was going into rigor and he needed a doctor and some medication.

237. It was the attitude of the nurse that was so disdainful and this is why I wrote a complaint: it's the only time we really encountered it. I was just like, I'm sorry I'm inconveniencing you here, but my son's taking a spike.

238. I remember the nurses sitting chatting round the nursing staff station. I hasten to say staff need to be able to decompress. They need to be able to chat. They need to be able to stand round the watercooler and complain about each other because we all get to do it. But really when it got to a stage where I had asked for help on a couple of occasions and they're more interested in chatting about

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the Christmas night out, who was going and who wasn't going. It was clear that I was an inconvenience to them. It was just complete disregard.

239. It was an imposition for them to come along. Or it felt like we were an imposition. Fair enough, they're having a bad day or they might not like me, but their personal thoughts about the situation shouldn't have influenced their level of treatment and I really felt that in ortho.

240. The nurse in question was called [REDACTED], and sticking up for [REDACTED] maybe she just didn't have a clue about temperature spikes in chemo children. If [REDACTED] had had a broken leg, they might have been all over it but this was obviously out with her realm of knowledge. Maybe it felt as if I was being a pushy parent. I think fundamentally she didn't have the expertise and knowledge to deal with the situation and that put [REDACTED] in the red. I felt we moved from the black to the red there. That was very dangerous territory and that wasn't good.

241. On reflection that was what the Schiehallion staff warned us about. That's why we were warned to keep an eye out. It was the joke afterwards. Did you get ortho? No. Oh then you're lucky. Where did you get? What have we got with other parents? Do you go to 2E cardio? 2E's great. Don't go to ortho. Avoid ortho. That was the chat between the parents.

242. Afterwards we were told by the Schiehallion nurses, next time this happens, come and speak to us. They told us to throw a flare up and they would come and deal with this. They told us that we shouldn't have to go through that. They were disgusted about the level of care.

243. I wrote a formal complaint following this experience and the Health Board responded. Despite what they say in their response, they were not monitoring adequately. I was reeling, to be honest. The concerning thing was I wrote a complaint immediately after the admission and 6 weeks later I have not received a response. I chased it on the 15 and 22 January 2019. It wasn't until the end of

January 2019 that we received a response, eight weeks later. I speak about the complaint in more detail later on.

244. In the orthopaedics ward, the nursing staff in general didn't have the expertise to deal with [REDACTED]. If they had knowledge and expertise to deal with [REDACTED], they wouldn't have treated him as such an inconvenience. Now the staff in every other ward, even if they didn't have the experience, professionalism kicked in and they upped their game to meet [REDACTED]'s needs. In ortho, they didn't and that is why we complained. If it was a line infection rather than a reaction to the chemotherapy that cause the temperature spike, we would have not been in a good place. In surgery, the staff made an effort to find doctors. In ortho they didn't bother. I shudder to think what the outcome might have been if it were something more serious, as we were not in a good place with the staff on that ward. They didn't have a clue.

245. We ended back at ortho and [REDACTED]'s last treatment was in ortho. To give [REDACTED] her due, it was frosty but she was diligent. She couldn't help but not be diligent. We ended up in Ward 3C again because Ward 6A had moved and was closed due to fungal issues. It must have been the start of 2019.

246. In wards such as ward 3C, there was infrastructure for [REDACTED] to play. He could go and play in the playroom but I wouldn't trust them as far as I could throw them because the protocols in their playrooms were very different to Schiehallion protocols. They weren't cleaned anywhere near as much. So although the infrastructure was there, the protocols weren't and that was limiting. If [REDACTED] wanted to use a PlayStation in Schiehallion these were issued. In most other wards you could just go, take one, and again we just cleaned it top to bottom. I trusted nothing.

Fungal issues - Closure of Ward 6A QEUH: January 2019

247. In January 2019, when Ward 6A QEUH was closed due to fungal issues on the ward. The ward was moved to the Clinical Decisions Unit (“CDU”) in the RHC. It was the only time I actually broke down throughout this whole period. When news broke about this move, I felt like I couldn’t cope with it. I said to Professor Gibson, I can cope with my son’s cancer, we can deal with that. I told her that I couldn’t cope with not knowing where we’re going to be admitted in the hospital. I felt safer with Professor Gibson and the staff in Schiehallion. I didn't feel safe anywhere else.

248. That put a lot of strain on me. The infection showed what could happen if he had an infection, what could happen if his body went wrong. Ortho showed us what happens if the care went wrong. The two combined meant that every time we walked in we just wanted to go to Schiehallion – wherever they were.

249. You can put up with not having a playroom, you can put up with not having a cup of tea because at least you know the care was so much better than anywhere else. This move just turned up the level of anxiety and stress.

250. I was very aware speaking to the professor that it wasn’t her fault. This was out with her control. She would rather this wasn’t happening. All I wanted to flag was we are dealing with all these concerns and every time we are admitted it is just so much stress. I flagged with her we went from being, “please don’t end up in hospital over Christmas”, to, “as long as we end up in Schiehallion over Christmas, we don’t care.”

251. I was also aware that this must be impacting them, so how does that impact their work? I was at the end of my tether at that point. Professor Gibson was great. I would have hated to be standing in her shoes, going round telling people, “we’re going to move again.” Imagine having to do that. I really felt for her because

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we're in it but we're only dealing with our own children. She's dealing with a ward full of children and she knows what happens when it goes wrong.

252. We didn't get much notice of the move. It was days not weeks. I'm sure there was a letter from the hospital, but the letter might have come out after we were told. Colette might be better placed to speak to this detail.

253. Prior to the move, Ward 6A was busy. There was lots of stuff going on. It was like moving house, and again the auxiliaries and the nurses bore the brunt of it. Hats off to their professionalism because it was an upheaval. The staff made it fun. For us it was the fact you're having to pack up your room and put it all away; it was just like moving a hotel room. It sucks. We made it as fun as we could and we all worked together.

254. We transferred to CDU which was a different ward. There were some good points about that. There was a central area the kids could go and play at; so that was great. We were also close to the PICU which was just up the stairs, and it had a parents' kitchen so you could get to there really easily.

255. CDU was also on the ground floor level so when ■ and ■ came in to see we could go out and play in the atrium, because there was nowhere to play. Again, that was a bit of a risk if there was potential disease issues, but we could go out and play.

256. At the time the thought of the move felt like quite a lot for me. We made it fun though and the staff did really well. Ru was the auxiliary there and we scooted down on the bed and ■ sat on the bed and Ru pushed it. ■ skooshed water out of a syringe at people going past, like a pirate ship.

257. It was a move; another upheaval: it was another set of variables. It was another nail in the coffin of the realisation that this environment isn't working. It was another flag up that it was going to be a while before we were back in ward 2A.

Communication about the move from ward 6A QEUH to CDU RHC: January 2019

258. I think there were some letters from the hospital. Colette very much was much more aware of what went on in the background. She was on the Facebook page and she's better at that. I did the heavy lift going in to the hospital. She did the intelligent stuff.

259. From what I understood, there was a fungal issue in Ward 6A and I assume it was airborne because they were using HEPA filters in the ward. Kids were being treated with antifungals as a preventative medication. Doctor Ronghe said that shouldn't get the anti-fungals because it would work against some of his medication, and in particular Vinc. In addition [REDACTED] was in an okay place at that point; his counts were okay and the hope was that he would be at low risk of picking up a fungal infection.

260. There were filters in the rooms in 6A, which were better than getting the fungus but not very good and they are a bit noisy.

261. It didn't impact us really. It raised the anxiety levels though. Could there have been more information? Probably. There was probably more information about that than there was regarding line infections that the kids were getting on the wards; so the hospital were learning. In these situations, you can never have enough information.

262. I did wonder if the fungal issue was affecting Ward 6A, and whether it was in every other ward. I don't remember ever seeing a HEPA filter in one of the outlying wards. It was same with the water filters, there were filter water filters in Schiehallion but they didn't have any in post-surgical. Should there have been? I

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don't know. It took time for it to filter out to other wards because they didn't have the crisis kids. Was that another thing that didn't filter out very quickly? Possibly.

End of ██████'s treatment: April 2019

263. ██████'s treatment ended on 4 April 2019 and he had his port removed not long after that. Following the completion of his treatment, ██████ attends at the hospital for check-ups. First of all it was three monthly, now it is six monthly follow ups where he has a scan just to check that he's okay and that there's nothing come back.

WATER EVENTS: OBSERVATIONS ABOUT WATER SYSTEMS

264. When in ward 2A we had been told to drink bottled water and we were told not to drink from the tap. We were told not to brush our teeth using tap water but to use bottled water. I can't remember the specific time when someone said at the start, but I'm sure we were told only use bottled water in the kettle and just drink bottled water. We were told that there had been an issue with the water before we arrived (by multiple people including nurses and domestic staff), and to use bottled water for drinking and brushing teeth. There were signs at the sinks that told us not to put anything down the drains.

265. If we were given bottled water on the other wards, it was different from the one give in Schiehallion. The one in Schiehallion was nicer, the bottled water in the other wards was really powdery and salty. In the other kitchens and hot water points throughout the hospital, I do not remember seeing any signs which told people not to drink the tap water. It was just in Schiehallion. The bottled water was brought into 2A first of all and then it was rolled out over the whole hospital over a period of approximately 2-3 weeks.

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PHYSICAL EFFECTS ON

266. ██████ got a line infection and that hit him when he was most vulnerable. It was hospital acquired. Right now I can't say what the entire physical impact of the line infection was because we don't know. But it must have had an impact on him, because his immune system was the lowest that it could ever be and then he got an infection on top of that. It would have been a lot easier if we didn't have it. And let's not beat around the bush, he was put in a situation that was life threatening.

EMOTIONAL EFFECT

On

267. In terms of the emotional effect on ██████, Colette and I tried to offset it as much as we could. We have to tell ourselves that as parents that we did as much as we could to offset any potential emotional effects. ██████ was very, very good at making the best of a bad situation. It will have had impacts. ██████ has probably picked up the anxiety from us. We tried to shield him as much as we could but it wasn't normal. There was no continuity, he needed to have continuity. He needed to have normality and he needed to be able to be a wee boy. He needed to be able to interact with people who are going through the same things. And he didn't have that opportunity when ward 2A closed.

268. It's a testament to him that he has bounced back as well as he has, or we feel that he has. We've had to do an awful lot of work with him. We still regularly go out for wee walks where I ask how he is doing. I ask him how he feels and he's still quite positive about it. But there was an awful lot of impact. Whether that would have been there or not, I don't know. But the impact of the issues related to the building put an awful lot of additional stress that wasn't necessary on him and all of us.

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269. It also meant that he had to undergo physical things which really weren't fun. Because when he wasn't getting treated in Schiehallion, his actual level of care was not as good therefore he had to endure stuff that wasn't fun like getting people sticking needles five times in to his muscles; like having to be pinned down to get a needle into his port or to insert a cannula. All the stuff that he shouldn't have to go through.

270. I think there will a bit of this that only time will tell. I'm more than aware that this could come and bite us on the backsides in his teens. This was a traumatic thing, and we're aware of it. We see these clouds on the horizon; it must have had an impact. I couldn't have come out of it as positively as he did. He's done really well but it is going to have an impact.

On the witness

271. It was tough. I'll be honest. Whether that was cancer or whether that was the issues in the hospital, I will always look at this as being a marathon. When was diagnosed, my wife and I said, whatever happens with us, it doesn't matter as long as [REDACTED] comes out of this healthy. Everything else isn't important. We had to shelve everything else and just get with it. We, kind of, knew it was going to be a bit of a marathon.

272. But it went on and on and it felt like we were running uphill. We were always running uphill. I hope to God this is the most stressful thing in our lives. The additional worries of not knowing where you're going to end up in the hospital, of not knowing what ward, or not knowing whether the infrastructure was going to poison my son and if it was going to kill my son. Brutal, but cards on the table. Is the building going to kill my son? Is this the ten per cent? Is this where it goes wrong? And that's hard. That's hard.

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273. I knew the cancer could kill my son. But I didn't expect the building to be doing it. The building and the infrastructure was as much of a concern as the cancer itself because the cancer was being treated and was a known variable. The chemo was either going to work or it wasn't, full stop. We can't do anything about it. The building was an additional bit we just didn't need.

274. My wife and I's bounce back from this was hard. I think it was a lot harder than maybe it would have been had it not been for the building issues. I think we were much lower down because of this.

275. It took us an awful lot longer to get back up. Colette's got a lot of help through some of the charities following what happened to her when [REDACTED] had the line infection. They are using phrases like post-traumatic impact. Seeing going through this and his line infections, it had a huge impact on her and therefore on us.

276. The general rundown of me meant that by the end of this, I was done. I am very lucky to have a supportive work environment because if I hadn't had that, I wouldn't have been able to carry on to be honest. I was just done. My work was great. I said to my work, I'm struggling. I had gone from a person that was dealing with my son's cancer and the issues related to that, to going back to work. There was not really much space to get my head back in to it. They told me to do what I had to do. They told me "we will support you, we will work with you." If my work was old school, I would be out of a job.

277. The stuff that I fixated on, the stuff that I struggled with wasn't [REDACTED]'s cancer. It was the constant state of stress, not knowing what was next which is directly related to the impact of the issues with the building. That's what really sent me off the rails.

278. It was the huge responsibility I felt that I had to get everything right going in to that room, getting everything set up. If I didn't get it right and I didn't manage the

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situation properly, and [REDACTED] did spike, it was on me as the person that went in first. I couldn't trust any of the nurses and doctors in the other wards, unless it was in Schiehallion. I could only ever relax in Schiehallion.

279. Schiehallion deals with immunocompromised children differently. We were made aware of that from the way the staff responded to [REDACTED], and that was right from the start of his treatment. There were a lot of procedures in place for these children, for example when you went in to A&E, we were kept separate from the others in the waiting area because the staff didn't want [REDACTED] in a place where he could pick up bugs.
280. We were very much made aware that Schiehallion kids are sailing close to the wind, and the level of care in Schiehallion was appropriate for that sailing close to the wind. Other people might not necessarily be as aware of how touch and go it can be, so therefore we as parents had to keep an eye on things as well. It's on us as much as the nurses and doctors.
281. That was really useful because it meant that we were able to go into these situations when [REDACTED] was in other wards and we were aware. The incident with the line infection was a great learning curve for us.
282. Whilst we didn't have a huge amount of control over that ten per cent we did have some influence there. The kid's got cancer. I felt that we couldn't trust anything unless we were in Schiehallion. That's it. We cannot trust anything and anyone. We couldn't trust anyone else's care. A lot of the time those fears were unfounded, but because of those fears I couldn't take my foot off the gas.
283. It is really important that we don't go in to every hospital ward and go, oh this is terrible. There was an awful lot of really good doctors and nurses in that hospital. Particularly those in units which are used to dealing with critical children or children that can deteriorate very quickly, because just as oncology kids are sailing close to the wind, cardiac kids are sailing close to the wind in a very

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different way. PICU are sailing close to the wind in a very different way. We've not got the bragging rights for being the only people that have very seriously ill children.

284. When we went in to wards where there were children that were very seriously ill, we definitely got treated better.

COMMUNICATION

General

285. I think communication from the hospital with parents could have been better. I'm sure the management group who are sitting at the other side of this will agree. The closure of ward 2A and the move to 6A was a knee jerk reaction. There should have been more strategising on their part about how to deal with this in the long term. There needed to be better communication about that, the plan A, plan B, plan C. And there wasn't. It wasn't there. After a period of time we knew we were not going back to Ward 2A anytime soon, it was utterly obvious that we were going to still be in other wards for a long period of time. We started working round it.

286. When we went to the meetings with the Health Secretary we, and other parents were flagging the issues that we had experienced. She told us that there was going to be an investigation and then they would response to our questions. They probably had a good idea what the problems are, for example poor design/construction/maintenance. I'm not the expert on it but there is probably going to be a problem with the pipe system. There must have been an expert at the health board end, at the hospital end, at the government end who could have shed some light on the issue and how to quickly deal with it. If there was this, it was not communicated to us i.e. drains have been badly installed we need to rip them out and start again.

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287. The hospital didn't seem to have any strategies about how to deal with the problems that presented with the building, as in the strategy of how to deal with the symptoms. They did not have a strategy to deal with the root causes either, and I found that quite annoying. They did not have a strategy that addressed the capacity issues that arose when they closed Wards 2A and 2B. They did not deal with the fact that there was a loss of facilities for the children. It did have huge impacts and we flagged that on numerous occasions with staff on the ward and at the meeting with the Health Secretary.

288. In terms of whether communication has changed or improved at all, I don't know. I've pulled away from it. Colette deals with that now. [REDACTED] will always be a cancer kid and just because you ring the bell doesn't mean it stops, because in theory we can go tomorrow and it could be back. You've got to be aware of that. But on the other hand, I don't really want to live in this world anymore. I don't mind doing this, I think speaking to the inquiry is a good thing because this is a positive thing. But for me it is done. It is put to bed. I'm not running away from it, it's just that it's time to move on to the next stage of our lives.

Communication - Meeting with Jeane Freeman: 2019

289. Pre-lockdown in the autumn or winter of 2019, Colette and I attended a meeting with Jeane Freeman, the Health Secretary. I don't know the date. It took place at a hotel in Glasgow next to Central Station. There were a number of other families there. At this meeting there were a lot of people that have gone through a lot. These sorts of meetings are an opportunity for people to offload, particularly when you're dealing with a politician.

290. I had concerns going in to this, that it might just turning in to a bitching match. It wasn't. It was quite a good positive thing. It was nice to be listened to finally. For us, it was the first occasion that someone's actually gone, okay, let's pull our fingers out and look at this. There were other families at that meeting that were

more vocal than us, and everyone was quite rightly upset with the situation. People have been through a lot.

291. It was a useful meeting because we had an opportunity to raise our concerns. A lot of the concerns raised were specific to the line infections that a number of children had contracted. Towards the end Colette and I got opportunities to raise concerns about infrastructural stuff. So for example we asked why was there still no a playroom in ward 6A? Following that meeting the kids got a playroom. You think, why is it taking so long to get a blooming playroom? Why does it take us speaking the health minister to get a playroom? It was useful thing and hopefully kicked the process forward. It was good even just to be heard. That's the thing, even if nothing changed, it's nice for people to listen to you and respond to your concerns.

COMPLAINT

292. I made a complaint following the admission to Ward 3C in December 2018. I received a response from the Health Board 8 weeks later but I had to chase it twice. The Health Board were apologetic and they identified more training for staff. I don't actually know if there were any other repercussions for staff, but there should have been

293. The response to the complaint didn't really allay my concerns. I was up to ten already. You go in to hospital assuming that you're going to get treated with respect and to the appropriate manner. The water issue flagged that the infrastructure and the environment was not set up for our children to be treated properly: that immediately reduced your level of trust in the environment.

294. Going to a ward where the level of care of treatment wasn't appropriate resulted in low levels of trust in the care and staff. The low level of trust in the environment and the care meant that trust was gone completely. As a result I was more concerned and had higher levels of anxiety.

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THE INDEPENDENT CASE NOTE REVIEW

295. ██████████ was included in the Independent Case Note Review conducted by Mike Stevens. Both Colette and I thought it was really good. We asked a lot of questions and they listened to us. It was nice to actually find some information out; that was the first and only time where we were given a lot of key information about ██████████'s infection. Colette waded through the report, it was a big document. I didn't read the main document.
296. Following receipt of the report we were provided with more information than we've ever had. There were bits of information where we wanted to know more. Specifically there were questions about where ██████████ was on the spectrum of likelihood of his infection being hospital acquired. Dr Ronghe had told us it was hospital acquired, and I trust him more than the review. The review itself it had said there were people that were highly likely to have contacted a hospital acquired infection that was attributed to the environmental issues in the building, and people that were less highly likely to be. Colette asked where was on the spectrum. They let us ask questions. It was good that there was dialogue rather than, "we're just telling you this".
297. Colette and I met with the panel members to discuss ██████████'s individual report. That meeting took place in Spring 2021. ██████████ was one of the only children who contracted Serratia Marcesens. They confirmed that it was likely to be hospital acquired. We were able to ask the doctors on the panel questions, such as after ██████████'s surgery why he went to post-surgical ward rather than Schiehallion. The doctor who we spoke to had trained Dr Ronghe and he was very complimentary about him and that was good. We felt that we were dealing with someone that had surgical knowledge and oncology knowledge all of which is relevant to ██████████'s case. He told us it was normal to go in to a post-surgical ward, rather than back to an oncology ward because post-surgical was

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used to dealing with patients coming out of surgery. That was fine and it made sense. However we didn't expect him to get a line infection in surgery.

298. The case note review was a good process. Fundamentally it flags that it's good to get information that we weren't getting. I think that any information provided is positive. There were periods where we just didn't have that information and it really highlighted that the more information we can have, the better it is for us.

OVERSIGHT BOARD/REPRESENTATIVE GROUPS

299. I am not aware of the work of the Oversight Board and I have not had any interaction with them.

300. I am not a member of any groups. Colette does a lot of Facebook stuff and is a member of some groups.

CONCLUDING COMMENTS

301. I have mixed feelings about the hospital now. Colette and I are half full rather than half empty in our approach. When we go to hospital now, [REDACTED] still bounces in. He's still quite positive about it. We worked really, really hard, both during treatment and after treatment to not turn it in to Castle Grayskull, or whatever scary place there is. Fundamentally the hospital staff saved our son's life. That's all that mattered. We have a son. When we first walked in through those hospital doors, [REDACTED] was a dead boy walking. We walked out of that building and hopefully cancer is not going to be an issue again.

302. To some extent whatever we went through, doesn't matter. I have a son that's alive. Fundamentally that is the most important thing. I bless the hospital doctors and nurses who do that job.

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303. There are periods where we look back at the experience in the hospital which are fun. You know some people might think how can you be positive about sitting in an oncology ward? The nurses, the doctors, the cleaning staff were just great. They did such a wonderful job. It's just only a shame that life was made so difficult for them, and for us because some idiot construction worker or designer who can't build or design a bloody hospital. I feel pity for them having to deal with this scenario.
304. Whether the hospital dealt with the situation as well as they could have done is a matter of question, and that is what this inquiry is about. The hospital should have dealt with the issues in the building, they had to deal with them. They put our kids' lives at risk.
305. The people that designed and installed that hospital building should be getting their arses kicked. I have anger towards these people because the level of construction is appalling.
306. There needs to be a level of accountability and responsibility for those people that commissioned the work, that built the hospital and that signed off on the work. In addition the resulting situation wasn't dealt with as well as it should have been. This process could have been easier for us all. My major anger is directed towards the people that did the work, not the people that had to cope with it.
307. The people like, Dr Ronghe and all these other doctors and nurses have been dealt a really bad hand. They were dealing with and trying to treat really sick kids in an environment that's not fit for purpose. The building is not fit for purpose and it's toxic; it nearly killed my child. That's brutal. The building nearly killed my child. Dr Ronghe didn't install the building. The contractors did and that's who I have issue with.

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308. Would it have made life easier if we were communicated with more regularly about what was going on? Yes. Fundamentally yes, it would have made my life easier. Would it have been easier if we had a playroom and access to facilities? Would [REDACTED] have less emotional shrapnel if the environment was better set up? Would we have less emotional shrapnel? Probably yes. But my focus of anger is really directed at the people that carried out the work on that building. I don't know how Dr Ronghe's still working because if I was him, I would have shut down. I don't know how half the nurses haven't given up. Or the cleaners. It's a testament to them to be able to work under such conditions.

309. As regards the health board, there was very little information and action that came from them. They should have been pulling their fingers out. Fundamentally the buck stops with them; they needed to be on this. It felt like they were dodging bullets. It was the type of problem where it would have been better if they went, "let's look at who's to blame later, but more importantly let's deal with the symptoms, let's deal with it now. Let's sort it now and mop up the pieces later".

310. I think we're still in the position where we don't know what has happened. We're still at a point where whatever problems that there are, have not been solved. They're still working at it. What we're doing here with the public inquiry is very important. However what is more important is that the situation must be sorted, and I feel that the health board are still waiting to find out who's responsible before they actually go and deal with the issues with the building. The need to get it sorted; they need to get it put to bed. They know how the children died or how close some came to dying due to issues in the hospital.

311. My concern and annoyance is with the people who built the hospital and then with the health board. Everyone else is fine. The doctors, nurses, cleaners; I feel pity for them. Imagine having to work in the building. It hasn't stopped for them. They're still in it.

312. In terms of any ongoing concerns about patient safety and the hospital building, Colette and I discuss how we would deal with ██████████ and a return to the hospital if his cancer came back. If we are in that situation again, and Schiehallion is not reinstated, we have discussed moving to Edinburgh to access their facilities and that's really summing it up.

313. If ██████████'s cancer comes back, the big concern for me would be that his numbers for fatality move from one in ten to a third. I'm majorly concerned about that. The thing is Dr Ronghe's in the RHC and he is great. We don't want to lose Dr Ronghe. But a huge concern is also be going back in to the hospital. Can I trust that building? In that situation the nature of the medication would require is robust and he's more likely to have reactions which would mean we would be in the hospital more often. No, I don't want that. I just don't want that.

314. In order to address my concerns about safety at that hospital, the health board has to get Schiehallion back in to ward 2A in the RHC. In order to make Ward 2A safe for these children, that probably means a ripping it out and starting again. The health board must implement proper procedures, whatever works that they're doing in the building. There should be a more robust sign off protocol for the works because they obviously don't have that given the problems with the building. There needs to be someone who has responsibility of checking up on the works, a clerk of works is the old school terminology. It is my view that the workman have obviously just skimmed things, that a view has been taken of "that'll do". Friday afternoon, that'll do. It appears that no one's checked up on the construction work and that's why we've got this situation with the issues with the building. They need a sign off procedure that's more robust, and that is carried out by someone that's independent and by someone who has knowledge of building and construction.

315. Let's hope that people learn and move on forward from all of this.

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316. I believe that the facts stated in this witness statement are true. I understand that this statement may form part of the evidence before the Inquiry and be published on the Inquiry's website.

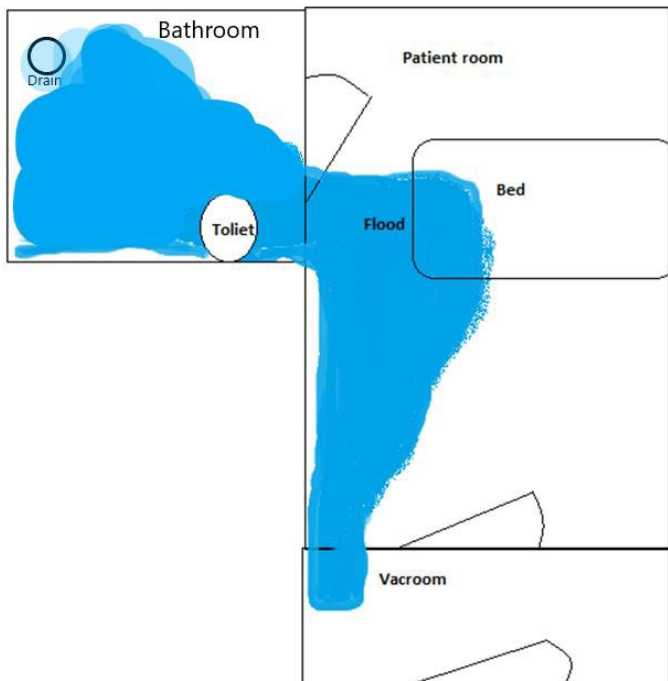
Appendix 1 – CAG/01 – Timeline**2018**

- 04/07 Discoloured Urine – thought from eating beetroot
- 05/07 Blood in urine – Alnwick out of hours – Antibiotics given and urine culture taken 09/07 Phone Alnwick GP – Culture clear advised to follow up with own GP
- 13/07 Urine sample to our GP and 2nd antibiotics given with bloods booked for Monday 16/07 Bloods taken, Urine cultures clear.
- 17/07 Bloods showed anaemia – scan and renal referral made. 24/07 Blood in urine more prevalent (now scarlet)
- 25/07 GP call – Scan date is booked - nothing more can be done until scan appointment
- 29/07 Bumped abdomen while playing and went green, low appetite for the rest of the day then vomiting through night.
- 30/07 SCAN RAH : Scan revealed mass on kidney – referred straight to oncology. MRI confirms Kidney tumour, Wilms. Dr Ronghe now on board. Tumour 12cmx8cmx8cm. Admitted via CDU to Ward 2A room 10
- 31/07 CT and X ray confirms containment in the Kidney area. Plan to start Chemo asap. 01/08 Surgery to fit Hickman Line
- 02/08 Chemotherapy protocol started, Vincristine (Vinc) and Actinomycin
- 08/08 Discharged
- 09/08 Daycare 2B - Chemo, Vinc
- 10/08 Spike re-admitted to 2A room 10 via CDU
- 13/08 Discharged
- 16/03 Daycare 2B - Chemo, Vinc and Actinomycin
- 20/08 Day care presented with a black tongue – told to monitor.
- 23/08 Daycare 2B - Chemo, Vinc
- 24/08 Spike admitted through Daycare 2B to Ward 2A room 2? Our first Vac Room also first room where air con actually worked. Went into rigor for first time, and we were communicated how serious his was, Nurse Kat waited outside with meds to get best overlap.

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- 26/08 Showered in room and flooded the room as drains did not function properly. Water pooled along wall, under toilet, into room, and out into vacroom. Reported to staff – response was eyes rolled “yes loads of the drains are dodgy.”



- 27/08 Discharged
- 30/08 Daycare 2B – Chemo, Vinc
- 03/09 Daycare 2B - Blood work and pre- surgery meeting with anaesthetist and surgeon Ms Brinley. 3.30 at surgical ward 3B for admission. Room not ready so had to wait in playroom until room was ready. We cleaned the surfaces down and on lifting the bed guard found it to be covered in brown/red dried matter. Not sure if blood, faecal matter or chemicals from operation. Bed was replaced. Not in room appropriate for immunocompromised patient i.e. protocol/procedures is for vac room. No filters on taps. Also different general failing of protocols i.e. reduced cleaning regime/dirty; all play equipment/areas accessible to everyone and not just patients (also cleaning of play area and equipment not as stringent) therefore unable to access these spaces/facilities due to risk of infection. Patient care different to chemo wards. Chemo wards do not have yr1 (1st year doctors) as

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these doctors do not have the experience and practical skill necessary for care of chemo kids. In both prep and post-surgical we had YR1 doctors.

- 04/09 Surgery. Kidney and tumour removed then into PICU
- 05/09 Temp spike through night – line infection suspected and antibiotics started.
- Transferred back to 3B – no vac seal doors, no water filters, yr1 doctors, different cleaning protocols for rooms as described above
- [REDACTED] had epidural still in place, morphine via PCA, and was on regular doses of antibiotics.
- 06/09 Line infection confirmed *Serratia Marcesens* Blood drawn via the line at 11.45. Emla cream applied to hands and feet to get peripheral bloods. (this is usually left for 30- 60mins to work). 40 mins later toxic shock. Taccacrdic (heart exceeding 200bpm); temp spike, rigor, vomiting. Had to go to front desk for help as no one around. Two YR1 docs arrived to help. – tried to get the peripheral draw. very distressed by this point.
- The nurses on the chemo ward would meticulously inspect the site and find the vein before applying the anaesthetic then come back later to take the blood – so they knew where to look. This YR1 doctor just put 4 patches on and came back later and started jaggig. After multiple attempts to get the blood they stopped trying. This left [REDACTED] with a real aversion/fear of needles, which required extensive work with the play team to reduce the impacts to a point that they could use a needle without me having to physically restrain him. Additional nurses also in the room. Colette Panic – had to leave.
- Dr Hettle – surgeon on call arrived and the room calmed. Line was ordered out of bounds. He got the blood draw first time while calmly talking with [REDACTED] about dinosaurs. Antibiotics were pushed, bolus was started and after an hour things settled down.
- 07/09 Visit from Dr Ronghe. Microbiology advise to place an antibiotic block in line (which required accessing it). In conversation with Dr Hettle, I raised concern this should not happen late afternoon on a Friday due to people leaving the building if care required. Dr Hettle agreed – not on a Friday afternoon 16.10 block put in.
- 40 min later toxic shock again due to toxic shower from line. Same symptoms as before. Duty docs call in Dr Kamal – jnr surgeon starts a bolus and gives ibuprofen

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to help manage temp. Consulting doctor from A and E (also on infection control) called in said "it's a poo bug". Wendy and Jane, Nurse Practitioners from Schiehallion, arrive and advise no more ibuprofen due to the dangers of ibuprofen for chemo-kids. Takes 90 min to stabilise, Kamal considers readmitting to PICU. Dr Hettle arrives (who had been in surgery) and makes plan to pull line.

- 08/09 Surgery Line out. Visit from Mr Davis Head surgeon on rounds.
- ██████████'s skin has become inflamed and itchy around the entire surgical site. Dermatology referral made
- 13/09 Discharged
- 17/09 Daycare 2B Meeting with Dr Ronghe and Dr Inkster (infection control). Apologised for line infection and they confirmed it was hospital acquired and should not have happened, and it came from drains. I made light of the issue saying that compared to what he went through in surgery this was not our biggest concern. The response to which was that the infection was the most concerning thing that happened during ██████████'s stay. Not the removal of a kidney, or removal of a cancerous growth, or stay in ICU. They confirmed one of six children ill at same time, part of ongoing issue with water system and they are planning to close ward
- 19/09 Daycare 2B antibiotics for ██████████
- 20/09 Daycare 2B Chemo, Vinc via cannula. Had to be pinned down and restrained by mum, dad and two nurses.
- 21/09 Spike admitted via 2B into ward 2A room 10 – all treatment via cannula and had to be pinned down again.
- 24/09 Discharged
- 26/09 Admission ward 1A Surgery - port fitted
- Transfer to 6A – adult ward 'New Schiehallion' with no facilities, fold down adult bed, no play room, no play team, no facilities for adults to get food/drink bar bottled water (Schiehallion had parents room with fridge, freezer, kettle and microwave). It was like going into full isolation with no contact/support from other patients, carers or play team. Not having general facilities like proper bed, access to kitchen, etc made a difficult experience much worse for the carer, you can't just leave a child to

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go and get a hot drink if it takes you 40 minutes. We travelled with insulated picnic bags with ice blocks to keep snacks cool, thermos flasks, snack noodles etc.

- 27/09 Chemo Vinc and Actinomycin and discharge
- 01/10 Daycare 6A infection neck wound site – given cream
- 04/10 Daycare 6A chemo Vinc
- 05/10 Spike admitted to 6A via CDU room 4
- 07/10 Discharged
- 08/10 Spike admitted to 6A via day-care room 21
- 11/10 Chemo Vinc, transfusion and discharge 13/10 Spike admitted to 6A via CDU room 23
- 16/11 Discharged
- 18/10 Daycare 6A- Chemo Vinc and Actinomycin
- 25/10 Daycare 6A- Chemo Vinc
- 1/11 Daycare 6A- Chemo Vinc
- 8/11 Daycare 6A- Chemo Vinc and Actinomycin
- 13/11 Spike 2E (cardio) admitted via Daycare 6A
- 22/11 Daycare 6A – bloods and dressing check
- 06/12 Daycare 6A - Chemo Vinc. Schiehallion confirm decant for another year X-ray and ultrasound.
- 07/12 Spike admitted via CDU to 3C Orthopaedics. 5 failed attempts to get port access. Cannula fitted to allow antibiotics to start. It was not until one of oncology Daycare's excellent nurses saw [REDACTED] that they could get line in. While struggling to get line in this was raising concerns with us in case of line infection like previously rather than standard chemo temperature spike. Very poor care in orthopaedics (especially considering heightened concerns due to issues accessing line). Failure to do observations at correct times, failure to respond to temperature spikes in timely manner (let's not forget his last line infection in 40 minute he went from ok to a room full of consultants discussing if he should be going to PICU), failure to administer medicine at correct timings causing discomfort and distress to the patient, and general lack of interest by the nursing staff (too busy standing

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round the nursing station chatting about the Christmas night out). I put in a complaint due to my concerns

- 09/12 Discharged
- 10/12 Dermatology – skin reaction to dressing a very difficult visit with being uncooperative due to the trauma of most recent stay. Wouldn't let Doc examine him, didn't want to be touched, poked or prodded.
- 11/12 Daycare 6A [REDACTED].
- 20/12 Daycare 6A - Chemo Vinc and Actinomycin
- 27/12 Daycare 6A – Chemo, Vinc
- 28/12 Spike- admitted 6A
- 31/12 Discharged


2019

- 10/01 Daycare 6A Chemo, Vinc and Actinomycin
- 17/01 Daycare 6A Chemo, Vinc
- Spike admitted 6A via Daycare
- Fungal issue on ward had been identified now HEPA filter installed in corridors and every room
- 19/01 Transferred with ward to CDU rm 19
- 20/01 Discharged
- 31/01 Daycare 1A Chemo, Vinc and Actinomycin
- 1/02 Spike admitted via Daycare 1A into CDU rm 19
- 4/02 Discharged
- 7/02 Daycare 1A Chemo, Vinc
- 9/02 Spike admitted via 2A (temp CDU) to CDU 12/02 Discharged
- 14/02 ENT follow up appointment
- 21/02 Daycare 6A Chemo, Vinc and Actinomycin
- 27/02 Spike admitted via Daycare 6A
- 3/03 Discharged
- 4/03 Daycare 6A Chemo, Vinc
- 15/03 Dermatology

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- 18/03 Daycare 6A Chemo, Vinc and Actinomycin
- 24/03 Admitted 6A

- 
- 25/03 Chemo Vinc – last dose
 - 26/03 Spike admitted via Daycare to 3C 27/03 Ultrasound and x-ray
 - 29/03 Discharged
 - 4/04 Daycare Dr Ronghe meeting
 - 8/04 Day Surgery 1A port removal surgery

Date not noted May/Jun – Daycare visit – chickenpox exposure – had to walk length of ward 6A to access Daycare. Raised potential infection risk at hospital board.