Scottish Hospitals Inquiry

Witness Statement of

Senga Crighton

WITNESS DETAILS

1. My name is Senga Crighton. I was born on [redacted]. I am [redacted] years old. I am a [redacted] for my son [redacted].

2. I am the mother of [redacted]. [redacted]'s date of birth is [redacted]. He is 16 years old.

3. I live with [redacted] in [redacted].

OVERVIEW

4. My son is [redacted]. [redacted] was diagnosed with Medulloblastoma in February 2018 when he was 12 years old. [redacted] was treated in the Royal Hospital for Children (RHC) and Queen Elizabeth University Hospital (QEUH) between March 2018 and November 2018. [redacted]'s treatment finished in September 2018. He attended both hospitals as an inpatient and as an outpatient regularly over that time. [redacted] still attends the QEUH for check-ups, as a result of his treatment.

5. [redacted] spent time in wards 2A, 2B of the RHC which are known as the Schiehallion Unit. The Schiehallion Unit is the kids' cancer ward. [redacted] also spent time in ward 3A, which is neurology, the Clinical Decision Unit (CDU)

and PICU, all within the RHC. Following the closure of the Schiehallion Unit in late 2018, [redacted] was treated on ward 6A of the QEUH which is where the Schiehallion Unit had moved to. I stayed with [redacted] during all of his admissions to hospital as an in-patient and an out-patient. I can speak to the experience which [redacted] and I had on these wards.

6. There are some specific events that I would like to mention. [redacted] suffered septic shock in September 2018 when he was a patient in ward 2A. He also contracted a line infection in 2018. There were issues with the water supply throughout [redacted]'s time at both hospitals. I believe that [redacted] was prescribed preventative antibiotics in 2018 but I am unsure if this was normal protocol for cancer treatment or if it was connected to issues with the water supply. There were ongoing construction works at the hospital throughout [redacted]'s time there which, in my view, impacted his experience. I will come on to talk about these events in more detail.

FAMILY BACKGROUND

7. I live with my son, [redacted] [redacted], in[redacted]. [redacted] has an older brother, my other son[redacted], who is[redacted]years old.[redacted]stays with his girlfriend. [redacted] and I don't see very often now but at one point they were just kind of typical boys, messing about with each other. The two of them did mixed martial arts but then got unwell and[redacted]met a girl and moved out. We see[redacted]now and again but just when he's playing his X-box and things. [redacted] and[redacted]get on well, they have ups and downs like any brothers.[redacted]is an amateur at Mixed Martial Arts (MMA), he's done a few fights, so he's done all right. [redacted]was doing the training with him before [redacted] took unwell.

8. [redacted] has autism so he's quite happy with peace and quiet and doing his own thing. He's into his board games and Lego, he watches Star Wars and Marvel

and all that kind of stuff. He'll come out his room when he wants to or he'll stay away, he'll say to me to get out of his room if he's playing his Lego. He'll do it on his terms. There was a time he didn't go to the MMA training and [redacted]thought [redacted] was kidding when he said he was not well.[redacted]feels bad about that now.

9. [redacted], had a wee group of pals that would come round but when he went to the high school he was kind of pulling away a wee bit anyway. [redacted]'s cousin, [redacted], is the same age as him and they have always been together. So it was mainly just the two of them. They were a lot quieter than the other kids. [redacted] was kind of seeing his friends now and again but when he started taking unwell, he never really saw much of them. Since this, I don't think they know how to speak to him because he is a different boy following the operation, he's struggled a wee bit. It's not badness from the other kids, they always ask about him but the only person he gets to see is his cousin. So, he really doesn't see anybody but he's got a befriender that comes in now for five hours, to break up his day. He's got that and his cousin, who comes down and spends some time with him along with his brother who visits now and again. His dad saw him for a while but he is not here again, he comes and goes.

10. [redacted] used to like going fishing and things but now, he only likes going to shops and buying more Star Wars stuff, he's quite happy doing that. He'll even go to into Tesco, to look at toys or jigsaws, but he's not one for going out. He sometimes goes into the amusements where he does play the 2p machines and he's quite easily pleased that way. When we were in isolation, I think it actually suited him for a little while, but he's not back out where he should be. [redacted] was left with posterior fossa syndrome due to the removal of a large tumour following an operation. I think he's self-conscious about his mouth with everything being different now because of the posterior fossa syndrome. Posterior fossa syndrome is a condition that sometimes develops

after surgery to remove a brain tumor in the posterior fossa region of the brain. The other four tumours that [redacted] had, did not contribute to the posterior fossa syndrome, and were treated with chemotherapy and radiotherapy.

11. [redacted] is at [redacted]. He's started [redacted], he was doing really well until he was not so well, then he was doing school while he was up at the hospital. We put a plan in place and he was actually doing his maths and English within Clinic 12. He was doing really well until he had the operation in his leg as they couldn't provide personal care within the school. We started doing a kind of Zoom thing. He did quite like school. He did like maths and English so he's decided to stay on and try and catch up on what he's missed.

SEQUENCE OF EVENTS: THE FAMILY'S EXPERIENCE AT RHC AND QEUH

Admission to hospital: February 2018

12. In October 2017 [redacted] was being sick and a bit unwell. At first, we thought it was his autism, causing anxiety. Then we thought it was a winter bug, but the winter bug would not go away. He got sore heads in the mornings, and did not have a lot of energy. After Christmas and New Year, he was eating less meals and being sick a lot. We were back and forward to the doctor's. I had to fight with the doctors because they said he's a fit young man. I don't think they realised how sick he was. On 30 January 2018 we practically carried him to the doctor's. They weighed him and took his bloods. [redacted] was then referred back to the doctors on 16 February to see him again but [redacted] didn't go. He didn't like going to the doctors but he really wasn't fit to go. The weight was falling off him and the doctor said he was going to refer [redacted] to paediatrics at this point because he was losing more and more weight.

13. On 17 February 2018 I decided to take [redacted] to Crosshouse Hospital A&E because he hadn't eaten or drank anything the previous night. They kept him in and put him on a drip, they did kidney scans, because they found he had high calcium in his blood. They did abdominal and lung x-rays. On 22 February 2018, they wanted to discharge him after he began eating, he had only eaten a banana. But I insisted on more tests before he was discharged because they still hadn't found out what was wrong. They did additional tests on 23 February and that night they phoned me to tell me they'd found something in his brain. [redacted] was transferred to the Clinical Decision Unit at the RHC in Glasgow that same night as there were no beds in ward 3A, which is the neurology ward.

[redacted]'s initial treatment: March 2018

14. It was Dr Campbell, from neurology, who spoke to me and she said she was going to give [redacted] an MRI that night. They did the MRI when I was there and Dr Campbell told me she couldn't be 100 percent sure but it looked like it was a medulloblastoma from where it was positioned. She said "I can't fully say hand on heart until I go in and operate. I can't see whether it's that or not. But that's what it looks like." She said she would discuss this with her colleagues who were also specialists, like herself. They put [redacted] on oral chemo from that point until the operation was done, because it was quite aggressive, so they wanted to put him under oral chemo right away.

15. On 24 February 2018 they found tumours in his head. [redacted] was given steroids. On 2 March he had the operation to remove the biggest tumour. He was in recovery for a couple of days in PICU and then he was in ward 3A in the RHC by 5 March 2018. In between, I'm not 100 per cent sure whether he went back to the Clinical Decision Unit until there was a bed in ward 3A. But I know he was definitely in ward 3A on 5 March. On 8 March, while he was still

in 3A, [redacted] had surgery under general anaesthetic to get his Hickman line in, to get prepared for his chemo.

Experience on ward 3A: early March 2018

16. When I first went up to the ward, I thought the staff knew what they were doing with the cancer treatment but I then realised that ward 3A wasn't the cancer ward. There had been a few issues with [redacted]'s Hickman line; they were supposed to put his feed off for surgery because he was getting put to sleep for it but the feed had been left on and they couldn't do the surgery. It was just one thing after another.

17. It was a bit chaotic and nobody seemed to know what they were doing. I just felt they were out of their depth sometimes with some of the cancer patients being in there, maybe because that wasn't their field, I don't know. I kept asking when we would go downstairs to ward 2A, and the nurse – maybe the Sister, with the blue uniform - kept saying we'd need to wait on a bed becoming available. I felt the staff within the ward were constantly being dismissive. Eventually I actually went downstairs to ward 2A, myself. I asked for the lady who was supposed to come and see me, whoever she was, and they told me she wasn't there. She knew I was coming down. I just said I wanted to know when [redacted] was moving.

18. The rooms are very dark in ward 3A. I think the room we were in was an internal one. If you were in a room on that side of the hospital, there was no window so it was quite dark. The ward was also in a circle but I didn't realise that at the time as our room was on the inside.

19. I just felt lost to be honest and was left to it. No one came in to care for [redacted] and nurses only came in to administer medication. This was unsettling

for both myself and [redacted]. My son had just been diagnosed with cancer, had an operation and when he woke up from his operation, he couldn't talk or anything and was fed through a tube. I had asked for help from a lot of people including the Social Worker or Psychologist and had to wait for them to actually come and see us.

20. They sent in play specialists but because [redacted] was just lying there, there wasn't really anything he could do. He did try a wee bit. I think they actually shut the playroom at that time, or the second time he was in there. The playroom was right at the end of the ward at the other side. [redacted] had drains and things in and he wasn't doing much so they would maybe bring colouring stuff or things like that for him to do. It was the play workers who would bring it in but they didn't appear very often. [redacted] only had two board games to play with in Ward 3A. This was around March time.

21. We were nearer the exit of ward 3A. I don't know whether the play workers forgot about you because they were up this end. The way I looked at it was that they were run off their feet and sometimes they could maybe not get to you, but that was just me thinking that was what's happening.

22. Outside ward 3A, there was a room up at the very top floor called the parents' room. It wasn't clean, it was bad. In ward 3A I actually had to ask for bacterial wipes. I would take them along to the parents' room to use on the microwave because other folks used it. The cleaner probably did clean it and then the parents would go in who were not as bothered. So you're kind of limited. People used to try and bring me stuff up from home for putting in the microwave but when you try to leave items in the fridges, they would go missing. There was a small fridge there and you could just put your name on your food. The room was wide open because it wasn't in the actual ward. It

was outside in the corridor, between wards 3A and 3B. Anybody could go in there from any ward.

23. [redacted] was in room 2, I think. It was quite dark and dingy, that one. In the room, there was a three drawer unit, for the meds. There was a bed and a sink for washing your hands, and a pull down bed. It was en-suite. I'd try to pull the bed down at about five, six o'clock on the children's ward because everyone's going to bed early. I'd be lying on my bed and it was bad enough with the bleeping of the feeding machines and blood pressure machines, and then you would have people making noise as if it's daytime. Within a day or two I was quite crabbit. I would openly tell the staff, "do you think you could have a wee bit of respect? It may be your nightshift but we've been up all day." They said they were trying to do their jobs. I thought it was just horrendous, and then the lack of sleep on top of everything else, no wonder you get emotional. I complained to the staff nurse a couple of times and she said she'd have a word with the staff to keep the noise down.

Experience on ward 2A: March to May 2018

24. Ward 2A is the Schiehallion ward. [redacted] was admitted there on 20 March 2018. It goes round in a kind of half-circle, like a big crescent. When you go in there's transplant rooms to start with, then you go round the corner and there's a desk, and then further along the corridor, right up at the back, there's a Teen Zone. It's run by the Teenage Cancer Trust. Across from the desk as you go in there's a small playroom, I don't think [redacted] was ever in that one either. [redacted] got his wheelchair when we were in ward 2A, eventually. He wasn't really bothered with the playroom, there were a lot of smaller kids in there and he just couldn't be bothered with them. At that point he was doing his radiotherapy when he was in ward 2A. He had six weeks of radium

Monday to Friday and by the time he came back, he was absolutely shattered, so sometimes he couldn't be around the playroom, he’d be shattered.

25. The play leaders brought stuff to [redacted]’s room for him to do things. They were different play leaders from ward 3A. They made bead chains and had colouring in, maybe painting, with wooden letters to paint. They had a music play therapy, and there were clowns. They tried to do stuff with him but the minute [redacted] started getting a bit better he just wanted out his room.

26. They’ve got the cinema within the hospital. They tell you what films are on, once or twice a week, and go round the wards and ask if any kids wanted to go to the cinema that night. Volunteers come in and take the kids down to the cinema. There would be volunteers on every ward to get them into the cinema, watch a film, and then return them back to the ward. [redacted] got to see Star Wars at one time, so he was happy enough. [redacted] only went to the cinema a couple of times but they kept saying, he couldn’t go if he had been under a general anaesthetic earlier in the day.

27. The parents’ room in ward 2A wasn’t bad. The woman was quite good at the cleaning in there. You had a microwave and hot water, that kind of thing. I’d be sitting there with my tub of porridge that you just had to put water in in the morning. They did offer toast, if you wanted it but the staff were just so busy so I just had my porridge. Then folk were starting to take other folk in there and it was becoming like a conference room. I constantly felt as if I was intruding whenever I went in because there were so many people there. Some people would not clean after themselves and I felt as if they had no respect. It ended up being only one parent at a time that was allowed in or you had to get a domestic staff member to get you stuff. We were only allowed around five minutes in the parent’s room after that. I would go down for my cup of tea

for five minutes. Once you were in source you were not allowed out your room and you couldn’t use the kitchen.

28. Patients would be put in source if, for example, they had a lot of sickness or loose stools or anything like that. They would tell you that you had to be put in source in case it was an infection of some kind. You have to be kept separate in case it spreads through the ward. I lost count of the amount of times [redacted] was in source and they only ever told me that it was an infection or that something had shown in his samples; they never said what was showing or what the infections were. At first I thought it was the chemo as it seemed to happen quite a lot, and absolutely every time he had chemo, even before the chemo, or if there was any bit of the runs or anything like that. [redacted] was on a feed, through the dietician but I don’t think it was made up from the water in the taps, it was brought up in bottles to run through his line so I don’t think the loose stools were related to the water in his feeds. I believe they were sterile bottles with the tube already attached, it was similar to a drip. I was always asking them why we were always in source. At one point, I think the full ward was in source, because you could see the stickers on people’s doors that would tell you not to enter. People couldn’t come in and see [redacted] as much as they could because he was in source. He couldn’t get out to see anybody even if he wanted to. It was a lot, and as I say, at one point I think probably you could count on the one hand how many kids were not actually in source.

29. The ward sister in charge would tell you if you were in source. They weren’t very keen on letting you out, to be honest. They would go and get what you needed, if you needed anything. The nurses were allowed in. I said to them that they were telling me I wasn’t allowed out to go to Marks & Spencer’s, but they were allowing nurses to go and have their lunch, and come back in and still come into my room. They were going in and out of everybody else’s room. They looked at me as if to say, what do you mean?

30. At around Easter time 2018 they shut the full ward down. The ward sister said they were trying to get on top of the infection control and that they had to shut the ward down to visitors and no one was allowed in to see [redacted]. They put a note on the door, saying ‘ward closed due to infection control,’ or something like that. I think I’ve got a picture of that as well [Picture SC/01 – Appendix 1]. I was actually distraught by then because [redacted] was in that room with not much happening to him and I was just sitting there. It was terrible. The ward was shut to all visitors for about two weeks, maybe. [redacted] was in source but was allowed out to get his radiotherapy at the Beatson. He would then come straight back and get stuck in the room again.

31. Staff were saying there were a lot of unexplained infections. I asked the staff, I cannot recall who, what they were but they didn’t give me names for the infections [redacted] had. They just said they didn’t know, he needed antibiotics and to be in source. It was just like an unexplained infection. I felt I didn’t get any information from anyone when I asked about the infections.

32. When [redacted] was in 2A he was in rooms 4, 5, 6, 15, 16, 19. Rooms 4, 5 and 6 were up at the Teen Zone, I think that was what it is called but I’m not sure. Some of them would have been when he was in for his four blocks of chemo in June, July, August and September. Those were the rooms that I remember when he was going in and out.

Discharge to CLIC Sargent House: May to November 2018

33. [redacted] was discharged from ward 2A, and went straight to CLIC Sargent on 16 May 2018, because we couldn’t go home. I was there before that, around April time. It’s a charity run house. They let us stay there because we couldn’t get the wheelchair down in the house and we were going back and forwards for

the chemo. So right up to the end of [redacted]'s treatment, we were going back and forwards. [redacted] was in the hospital getting his treatment, and then back to CLIC to do his physio as well.

34. When you go in to the CLIC house, there's a downstairs and an upstairs. In the downstairs there are three rooms with your own toilet, it's got a shared living room and a shared kitchen for three families at the most. There's also a dishwasher. You've got the back door which leads you out to a garden with a sitting area and the laundry room. They'll give you your own washing machine, one for each set of rooms. Any soiled stuff had to go in to pink bags. You couldn't chop and change washing machines, they liked to keep on top of who was using what machine, so you had to a specific machine to use.

35. Sometimes it was myself with [redacted], another lady across from us, with her son, and I think we had a mum and dad whose son was never out of hospital, who stayed in the other room. Everything was cleaned once or twice a day by the staff there. We didn't use dish towels, you used paper towels for everything. It's a nice clean environment.

36. [redacted] was back and forward because we were over there and couldn't go home between Monday and Friday. He would do school, physio, maybe cooking in the kitchen over in the hospital, just to get his day in. He would only go back up into the ward when he was due chemo and then the minute that chemo was done, he was back out into CLIC. He would have to go in to the hospital for the first week to ward 2A and he would get out on the Sunday, all going well. He did the two treatments and if everything was all right, he could then get out. We then went over to the hospital to ward 2B on the Tuesday after to get his vincristine, which is another type of chemo that gets pushed down the line separately. You have to leave days between the vincristine and the other treatment but if everything was alright, he would get back to CLIC.

Sometimes [redacted] was unwell and he couldn't get out so he was kept on ward 2A. That went on until September when he finished his last chemo. We didn't leave CLIC because I had to move house as well in the middle of all this. We were discharged from the ward on 30th September 2018, and we left CLIC on 24 November 2018.

HAI, admission to ward 6A and completion of treatment: September 2018

37. On around 25 September 2018, [redacted] went into ward 2A for his chemo. He had pus on his Hickman line that I had noticed previously. I pointed it out to the nurse but she said it looked okay and that I should just keep an eye on it. A nurse came and put a device on the Hickman line to withdraw the pus but this made no difference. The next day, [redacted] became unwell and his temperature spiked. They eventually took him straight into ICU. It wasn't until later that I found out [redacted] had developed septic shock.

38. [redacted] got out of PICU in the RHC on 28 September 2018 and they moved him to ward 6A in the adults' hospital. It was room 25 he was in and later they said they would discharge us to CLIC as it seemed safer. I can't remember who it was that said that. She said, it's maybe safer at CLIC than here. I don't know whether they thought that the line was infected. I know there were hundreds of kids having to get lines changed time after time.

39. [redacted] was only in ward 6A for 48 hours and he was in source for that time. At that point the domestics were bringing everything to us. By the time we were in 6A, I don't even know if there was a parents' room, and if there was, I was never in it.

40. Ward 6A was set out in a complete circle as well. The only thing better than 2A was that it was higher up and you could get a better view out the window, so you got more daylight in.

41. On 30 September 2018 they said to me [redacted] was safer going to CLIC, because it was only five minutes away. I don't know if it was safer because of all the infections that were happening but maybe he would have been better at CLIC.

42. That was us after that. We went over to the hospital for MRIs and kidney tests, and from there he finished the treatment. [redacted] got transferred down to [redacted], to the local hospital. Then it was just check-ups after that.

Experience in ward 3A: August 2020

43. [redacted] got his MRI scans every three months in 2019, in clinic 12 at the QEUH. It was to check that there was no more cancer or any tumour regrowth or anything like that. There seemed to be a build-up of fluid which was picked up right back at the start, there was a small trickle, they were leaving it to see what happened, because he wasn't really fit enough. That's when they decided to do the VP shunt, on 18 August 2020 because the fluid was starting to affect his balance and he was lethargic. He was admitted to ward 3A in the children's hospital, I think it's called neurology. This was for a week. He got a surgical procedure to get the VP shunt fitted by Doctor Campbell. Because of the fluid in the brain, they had to put a small tube inside his neck, at the side. It goes through his main artery in his neck, into his stomach. When the fluid gets to a certain level it flushes the overflow of fluid in the head, down into his stomach and he passes it out. That's just something that would never fix itself after his operation and he had the build-up until it affected him. That was the only time he was really an inpatient again, for the shunt.

Experience in ward 3C: March 2021

44. After [redacted]'s treatment, his leg wouldn't straighten fully and he couldn't get on to his feet properly. The leg was bent from 2 March 2018 and ironically, [redacted] went into hospital on 2 March 2021, exactly 3 years later. We tried everything to get him to straighten it, the skin shrunk because the leg was at a 45 degree angle, we tried Botox and physiotherapy but nothing worked. We had a consultation with Dr McCall in orthopaedics in January 2021 and she put a stookie on [redacted]'s leg for six weeks so it didn't regress. He then got the operation on the 3 March 2021 and was in ward 3C. Doctors thought this had happened to [redacted]'s leg, partly due to the posterior fossa syndrome, and maybe partly because it had been left in that position for so long as he would always sleep in the foetal position. The skin behind his knee had shrunk. He now has a hinge bracket inside his leg to allow him to straighten his knee. His leg is now 2cm shorter than the other leg because of the operation.

WATER: EVENTS INVOLVING WATER SYSTEMS

Water incidents in RHC: 2018

45. I used the water for washing my hands and showering. There wasn't really anywhere else. I was using it at first before I went to the CLIC Sargent. I also used the water at first, with [redacted], in ward 3A. I didn't notice filters in 3A, I think that all happened once we were in 2A. After [redacted] got a lot better, and I went to CLIC, I would stay with him in the ward till 10 at night and come back over for 7 in the morning.

46. I was a bit scared of drinking the water because I always wondered if that was what was wrong with [redacted]'s line. I had put him in the shower too in ward 3A

and in ward 2A. When I was washing [redacted] I was using tap water, and if we were making meals, and cups of tea, it was also that water we were using.

47. When I was in ward 2A in 2018, they put things onto the taps and they told me they were filters. They were put in the shower and they were put in the taps and the sink. All the filters were on the shower and the sinks within the rooms but there was no signage up. I think it was a company that put them on. I asked the guy who fitted them and why they were there. He told me he didn't know, that he had just been told to do it. That happened between March and May 2018. I think they got changed over again when I was in later on, with one of [redacted]'s chemos. So they were changed, in the short time that I was there, from start to finish of the chemo. That was between May and September 2018. The second time, the filters were changed to a different one, for whatever reason. The guy came in with boxes of these things and they were taking them off, putting the new ones on with a date on it. I think it was a company again, I don't think it was the hospital, but I might be wrong.

48. When [redacted] was in ward 6A in September 2018, I had to get the patient wipes because I couldn't really get him in the shower. I wasn't willing to use the shower, because I also found out that seemingly there was an infection in the water. I stopped using the water when I heard that and also because [redacted] didn't have much of an immune system. I didn't want him to have any other issues so I stopped using it before we moved to ward 6A.

49. They brought in portable sinks as well. We were all given these portable things to use in the room, a wee sealed thing with a wee basin at the top, you put the water below it and you shut it over and pumped the water through. If I remember rightly, you used your foot to pump the water. It was bottled water you had to use to pump it through. [redacted] was not going to let me use that on him because it wasn't that warm.

50. Anybody you asked said it was just a precaution, just in case. I can't recall who it was in particular but they would come in and blame the cleaners and the cleaning for the infection. I told them I didn't think it was the cleaners, the ones I had were great.

51. They said there was bottled water available. That was after we'd all been drinking the tap water, right enough. I was drinking it with my dinner. I've got bother with my kidneys and after [redacted] got out, I went to my GP because my kidney was sore. This was after [redacted] was discharged from hospital. I provided urine samples. The results were that I had developed a bacterial infection which the doctor had never heard of, called Raoultella Ornithinolytica, which is connected to water.

Water: communication

52. I have the bits of paper handed out about infection control. I got them up in ward 2A. I had a couple of handouts. It said it was something to do with the water. They wanted the filters on as a precaution and to keep on top of it, that kind of thing. It was nothing to worry about, that's what we kept getting told, nothing to worry about.

Issues impacting patient safety and care

53. At one point when we were in ward 3A, which we were only in for two weeks, so I think was in March 2018, one of the staff members, Donald, helped me try and get [redacted] in the shower. . [redacted] wasn't talking but he was making a lot of screaming noises. We tried to get [redacted] in the shower, but he couldn't really stand, so we're trying to hold him, and sit him on the chair, just to get him under the shower. [redacted] was distraught, it was extremely painful for him.

When I look back, I think that was hurting [redacted], just the water on him, was hurting him, because he'd never had that issue before. He had sensitivities all over his body following his operation. The staff wouldn't touch [redacted] to start with so he was just lying in his bed but when we did get him in the shower, he was kind of distraught. I thought, I'm not putting him through that again. We just used a bed bath, with a basin and a sponge. He was not as mobile and so trying to move him was difficult.

54. After [redacted]'s first operation, he had secretions in his mouth and he hated it. He had to get the big dry cloths, and I had to roll them up and put them in his mouth for the secretions. He used to keep them in his mouth because he hated that dribbling. I had an issue at one point because the staff said that he was using a lot of these cloths. They had a wee moan about how many cloths he was using to get rid of the secretions in his mouth.

55. I think sometimes they kind of forgot about [redacted]'s autism as well. They were just looking at what they were presented with about [redacted]'s condition, and forgetting about everything else. I don't know how many times I had to remind them of things. In ward 2A they tried to give me a room next to the desk. I told the nurses that we didn't want that room as it was too noisy because they congregated at that desk and phones were going. They eventually got [redacted] a pair of earphones because of the noises of the buzzers.

56. On 15 March 2018, the nurses forgot [redacted]'s chemo. I challenged them and I was told that it was higher grade staff who had the key to the drugs cupboard and they were in the process of handover. I said they'd better get the handover sorted and get the key and give my son his chemo. They said it was okay, it was only an hour or so. I told them it was actually two hours since they had forgotten to give him his chemo and if I hadn't remembered, who would have? I thought these people were going to be more professional than they

were being and they seemed to be forgetting a lot of things, that people's lives were in their hands, especially with medications and kids. After that I was on edge. I just thought they would know what they were doing with the cancer thing, but a lot of the time it was quite chaotic. They really didn't know what they were supposed to be doing, and what I took from that was that sometimes when they were asking about things, they would try and blame the Doctor for not passing information on, or they would try and blame the previous shift.

57. I was a residential child carer for social work. I told the staff that I work in a children's unit and you get handovers from shifts, so you are supposed to find out what happened before. I asked why they were going into handovers and not knowing what's happening with my child? There was one man in there who tried his best, his name was Donald. He was run off his feet because everyone wanted his help because he would do his job thoroughly and always gave 100% with the care he provided..

HEALTHCARE ASSOCIATED INFECTIONS

HAIs: events and physical impact

58. On 25 September 2018, [redacted] went into ward 2A to start that cycle of chemo and I showed the nurse the pus on [redacted]'s Hickman line. It was quite red round about it so they put one of these doughnut things on it, that was supposed to draw it out. The nurse said it looked okay but to keep an eye on it. I told her that it was yellow pus but she just said to keep an eye on it. The next day, [redacted] was quite unwell, he had a high-temperature, he was very swollen, his temperature spiked. They gave him stuff every four hours to try but nothing was working. 25 September was the day they were meant to start moving them all to the adult hospital. Everybody else was getting moved but

they couldn’t move [redacted] until he was stable. He was the last kid out of there. They didn’t tell me it was septic shock at that time, it was later on I found out, because they had to take him straight from there and they put him straight into ICU. I can’t recall which Doctor it was who told me it was septic shock.

59. [redacted] ended up unwell and he went into PICU in the RHC with septic shock, on 26 September 2018, instead of going to 6A, where he should have been going. He couldn’t be given his last bag of chemo as he wasn’t well enough. His heart rate had dropped, his blood pressure was up and he was flooded with antibiotics and given oxygen and that was it.

60. The Doctors were all around about him. Dr Murphy, the oncologist who gave his chemo, had come and all he’d done was touch him, and he said, did nobody think of doing that? There were a lot of doctors in the area, intensive care doctors up as well. I think they were all worried because I had already highlighted it. I don’t know whether they just didn’t bother and then they realised, oh, this could be serious.

61. [redacted] had a few infections and to treat the infections, they flushed [redacted]’s lines with antibiotics and they gave him medicines as well. I’ve got the names written down somewhere. [redacted] contracted the infections whilst in Ward 2A, he was never out of source when in that ward. It was terrible and had a big impact on my mental health. No visitors were allowed in source and we are unable to leave the room. It was mostly the nurses that would tell me about him having contracted the infections. The nurses were never able to tell us what infections [redacted] had contracted.

HAIs - delay in treatment and patient outcome

62. Because of the infection in September 2018, [redacted] wasn't allowed to get his last bag of chemo. I was worried that the last bag of chemo would make a difference to the results, because that was the end of his chemo treatment. I think [redacted] just didn't know what was going on. He couldn't stop shaking and I think I felt worse about that, than I did when they told me he had cancer. I couldn't believe he ended up with septic shock, because he had come through all that to end up with septic shock. Fortunately, it didn't have any long term effect on his health.

HAIs: communication

63. I was never told where the infections came from that [redacted] had. I just felt that if there was any type of infection it was as if they tried to put it onto you as if you, as if you weren't doing something right. They would ask things like, was [redacted] cleaning his hands? He was cleaning his hands; he was like that before he came into the hospital. I think sometimes, maybe they were looking to blame someone else.

64. They dealt with the infections as if it happened quite a lot, saying that these things happen with the chemo treatment and that kind of thing. That's the way that it was put it across to me. When [redacted] was put into source, in ward 6A, they just said it was quite serious as he had developed the sepsis and they were glad they caught it quickly.

PREVENTATIVE MEDICATION

65. When [redacted] first went into ward 2A he was prescribed Acyclovir and Posaconozole. He also got Septrin, Prophylactic painkillers and Baclofen anti-sickness drugs. He used to get something for bone marrow stimulation. [redacted] was on them for a long time. There was one time when I had phoned for

a repeat prescription and I remember Dr Murphy telling me we had to keep on them for a certain time. He was on them all the time throughout all the treatment but he still seemed to get some kind of infections, even with getting the drugs.

66. It's hard to say if the preventative medication has had left any physical effects. [redacted] was in a chair; he wasn't really active. There's times when he still gets very tired and lethargic. I don't know whether it's just that because he's been in the chair and he needs to build himself up, or whether it's damage that's been done. I won't really know until that gets looked at.

67. I asked why [redacted] was on all the medications, but they never really said much apart from it was to help with his chemo treatment, because of his lowered immune system.

EMOTIONAL EFFECTS

68. I think [redacted] got fed up and scared. He was just a bit unsure of what was happening; which made him question everything they were giving him as well.

69. My emotions were all over the place. It was just everything, I was dealing with the hospital and all their mistakes, and then trying to move house and it was just a nightmare. The best thing that happened was when I eventually got over to CLIC and was able to get some sleep because broken sleep and everything else on top of it, wasn't good. I ended up on anxiety medications as well, because I felt I did not want to lose the plot. I was quite assertive with the staff but I never swore, so I was quite pleased with myself because I easily could have.

70. On ward 3A nobody could give me answers to things. I'd just found out my son had cancer, he had to get an operation, he'd woken up from this operation, not talking, not doing anything and having to be fed through a tube. I felt that I was just left. A lot of the people that you're asking for help, they'd maybe get the social worker or the psychologist. You had to wait for them actually coming.

Patient outcome

71. [redacted] is due for an MRI at the end of July 2021, for the oncology side of things. I think they just check but I don't know whether they can check the shunt at the same time. Since March this year, it's just been regular follow-up visits for [redacted]'s leg. We're back up at the hospital again on 22nd July 2021, to orthopaedics.

COMMUNICATION: GENERAL

72. When it came to [redacted]'s care, for me, there was a lack of communication, or the communication systems that they used were not efficient enough. There were a lot of times I was having to tell them, "No, that's not what we said". I was usually right and it wasn't often that I wasn't. I just think the communication system was a big issue. Dr Campbell and Dr Murphy were very thorough in telling you things. When it came to the nurses, it was different, I had to find things out and they always said that they would have to ask somebody or they didn't listen to you, for example, the situation with [redacted]'s line and the sepsis. I didn't get much hope from that, especially as they were looking after my son.

73. There were times when [redacted] was supposed to be staying on a feed or it was to be upped and the nurse would say one thing and I would tell her that

another nurse had said something different about the feed. By the time they got hold of the original nurse, hours would have passed and my son's not had anything to eat. So it was silly wee things like that that made me think, surely there's a better way of doing this? The system is as good as the person that's putting the notes in. I said to them that I thought they were all on the one system, and that they all just added their wee bit in? I was told that it was only higher level people that could do that. I thought, what's the point in that, then?

74. I had a meeting with the lady that was in charge of the ward at the time, the Sister, I can't remember her name. It was after the chemo incident in March 2018. She was saying, you know, we try, and I said, I'm sorry, you maybe need to look at your communication policies or whatever you do, because they're not working, because that's all I hear. Whilst in Ward 3A, [redacted]'s soiled pyjamas shorts were just left on the floor on one occasion. He would wear pads which were not there, but the pyjama shorts were visibly soiled. They should have been getting bagged immediately but they were left on the floor. I complained to the sister in the ward. It never happened again and the sister blamed it on a lack of communication.

75. I mentioned earlier about ward 3, when the staff member who had the key for the controlled drugs cabinet. When I asked the nurse about it, she told me it was higher-grade staff that had the key, that they weren't allowed it. The person with the key was in at the handover so [redacted] didn't get his chemo on time.

76. The last couple of times I've been in the hospital, they seem to have been okay. I don't know if it was because they were shorter stays. The cracks appear when you're in longer. I think the Doctors that I've spoken to were fine, it was the nurses, really; they would always tell you they need to find out the answers or ask somebody else. The information in general has been quite

good, they go through everything with [redacted] and take their time. Even in the plaster room, the staff in there were wonderful, they talked to him. I tell them that they need to tell him everything they are going to do, before they do it, and they're good.

77. I'm a member of the closed Facebook group but I don't know when they started it up, or who started it up. I don't really go on it very often, because I'm not on the Schiehallion ward anymore. It was just if I needed a phone number or something like that. At the time there were things on it about the water but I didn't think about it at the time. I know some of the girls in the group but there's other people that I really don't know because they were maybe in before me. I think there are some parents that maybe asked about certain issues, or how do you do this, or how do you get Dr Murphy's medical secretary number? It was that kind of thing.

78. I think it's good to be able to sound off on the group because if you sound off to the nurses, everybody just gets upset. You can sound off to the group, whether you're right or wrong. Some of them have already been where you've been or they're further in the process and telling you what to do or kind of help with that. I think it's good for that.

COMPLAINTS

79. I was ready to make complaints when I was in the hospital, but they always talked me out of this. There were times when I was spoken to like a child, they would say things like, "I will come back when you are calm." That happened in any ward I was in, if I said that I was going to put a complaint in. The staff nurse in 3A eventually took me into her office and we had a meeting. She tried to talk it through. It was the same with 2A. Sometimes they would just walk away and say, I'll come back when you're calm, as if it's you. I would be trying

to ask a question and they would disregard it as if, they were the nurse and knew better. Most of the times I dealt with things there and then and the staff would try to fix the issue at that time.

80. I think Dr Murphy walked away from me one day when I was talking to him about the septic shock thing. I was still angry at the time because, by that time I knew about the water, and that the hospital environment had probably caused my son to have septic shock, and that was what I told him.

81. I also said the same thing to one of the nurses as well. I told her it was about the lies, making out as if it was our room or our cleanliness, instead of saying they thought it was about the water. I told them they were making it out that it was us. When [redacted] took septic shock I was up to high doh because I thought, I'm going through all this and this could have killed my son.

82. I think my complaints were dealt with appropriately, depending on who I spoke to. Doctor Murphy did try his best to get things sorted. It was the same with Doctor Campbell, she was straight on it. Doctor Campbell was the surgeon in ward 3A who did [redacted]'s brain operation.

83. In ward 2A the staff were moving around, like they weren't trying to be as quiet. It was just horrendous sometimes. During the night they were talking in a tone where you would think it was day time, not night time. I raised my concerns to the nurse in charge of the ward and she said she would have a word with them and keep it down a bit. I was trying to give them the benefit of the doubt. It would be alright for a bit and then it slipped back. I wasn't the only one that had to speak to them about the noise.

84. The hospital could have dealt with the complaints better but if I couldn't get the staff, or if they were busy, I felt I was getting lip service. The lasting impact

on me is that I used to think that the Doctors and nurses should know better than me, and that I could trust them fully however, now that is not the case.

OVERSIGHT BOARD / REPRESENTATIVE GROUPS

85. I have not heard about the Oversight Board. I'm part of a Whatsapp group which I think is a kind of informal patient and family representative group.

CASE NOTE REVIEW

86. I had a phone call from Jeane Freeman. I'd tried to phone her because we'd get letters in about the Case Note Review and I didn't know if my son was involved. The general letter came in first saying, [redacted] had septic shock so I phoned her up and left a message. She returned my call and I asked if she had heard anything else. She told me they still had a lot of kids to go through and [redacted] might not be one of the ones that they were looking at. It was as brief as that. I never heard anything from her after that. I still don't know if [redacted] was part of the Case Note Review.

87. That was the only contact I had with Jeane Freeman and I can't remember exactly when it was. I didn't go to any meetings with her.

CONCLUDING COMMENTS

88. I'm still wary every time we have to go in to the hospital. I probably still wouldn't use their water, even now. It's just the fear. I think they're trying to get on top of it, and the cleaning. What I did notice was that they are using disposable mops now, by the looks of it. That's an improvement, as far as I'm concerned.

89. I’m wary because if the hospital can cover things up, they can cover anything up and the trust that I used to have is no longer there. I’m not saying I don’t trust the doctors, when they’re doing their operations I’m just still wary because it can make a difference to your child.

90. I don’t trust the Health Board. I think they must have known that this would have come out eventually. Sometimes places are shut down to make big super-places that are not fit for purpose and cause umpteen problems. I just don’t get it. They should have been truthful with people.

91. The only concerns I would have now is if we had a repeat of the poor people that lost their lives through bacteria in the water, or the pigeon droppings, or whatever it was they say. I don’t know how they’re going to fix that because I don't know what these filters do, or if they’re doing the job they were supposed to.

92. How are they going to fix the water? How are they going to fix that? It’s such a big hospital. I think they need to get to the full underlying issue of what’s causing the bacteria in the water. Is it the land it’s on? Or is it something that the water board could fix? It’s a lot of money to waste, unless they’re doing a portable water thing, but that’s going to cost them a fortune.

93. Another concern I have is that [redacted] and I just missed the window falling out as well. This was around July 2018. We were going over for an appointment one day and missed that window falling out by a minute. It was an external window on the 10th floor. I asked what happened and I was advised that the glass window had fallen off and smashed. You could see the missing window from outside, it was at the right hand side of the adult entrance. I was advised by other parents that two windows had fallen out before in the past.

94. I'm okay with the communications now. While I was in the hospital, it was horrendous, everyone blamed each other, and the, "wasn't me", the, "I don't know about that". Are the doctors not writing their notes? It's a blame culture. I just wish they had been more truthful with us, because they were putting my child's life at risk. My son had to fight for his life, I didn't expect him to be having to fight again and again because of water issues. I don't think it's great what's happened up there and they should have been more truthful.

95. 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.

SC/01 – Appendix 1