

Scottish Hospitals Inquiry

Witness Statement of

Witness 6

WITNESS DETAILS

1. My name is Witness 6. [REDACTED]. [REDACTED]
[REDACTED].
2. [REDACTED]
[REDACTED].
3. [REDACTED]

OVERVIEW

4. My [REDACTED]. [REDACTED] was first diagnosed with Acute Lymphoblastic Leukaemia ("ALL") in [REDACTED] [REDACTED]
[REDACTED] was originally treated at Yorkhill and then at the Royal Hospital for Children ("RHC") between [REDACTED]. [REDACTED] attended the hospital as both an in-patient and out-patient for [REDACTED]. [REDACTED]
[REDACTED]. I have been unable to provide the Inquiry with a timeline showing the dates in which [REDACTED] attended hospital due to the time period between [REDACTED] last treatment and present date. I can't access any dates via [REDACTED] medical notes either as they are not in chronological order. [REDACTED]
[REDACTED]
[REDACTED].

5. [REDACTED] spent time in ward 2A, which was known as the Schiehallion Unit. Ward 2A took over the treatment and purpose of the old Yorkhill Schiehallion Unit. I stayed with [REDACTED] during most of [REDACTED] admissions to the hospital as an in-patient and out-patient. [REDACTED]
[REDACTED]. I can speak to the experience [REDACTED] and I had within ward 2A.

6. There are some specific events I would like to mention. When we moved over to the new RHC, we lost a lot of services that helped both parents and children, some of the facilities that were built for the move to enhance the RHC, were never even opened. Parents were isolated as were children as a result of this. [REDACTED] had a number of infections during [REDACTED] stay but I cannot recall a lot of the details and I was not told what they were at the time. I was never given information about the infections and it was always dismissed as being part of [REDACTED] treatment. I found out [REDACTED], that [REDACTED] had been on preventative medications. I will come on to talk about these issues in more detail.

FAMILY BACKGROUND

7. [REDACTED]
[REDACTED].

8. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

9. [REDACTED]
[REDACTED]
[REDACTED].

10. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

11. [REDACTED]
[REDACTED].

AMENITIES AT YORKHILL

12. [REDACTED] was diagnosed with ALL in [REDACTED] and was initially treated at the Schiehallion Unit at Yorkhill hospital for [REDACTED]. [REDACTED] had [REDACTED] port-a-cath fitted there which lasted [REDACTED] through-out [REDACTED] treatment. Yorkhill was a lovely hospital. It was a bit run down and needed a bit of a face lift but it was a functional hospital.

13. The service at Yorkhill was great. One example would be the blood tests and the time they took. Children would go to Day Care, to receive any treatment that was not required to be administered overnight. Before they went to Day Care, they would have to go and get their blood tests done at the blood clinic. This was a thumb prick test and by the time you had walked from the blood clinic to Day Care, the results were sitting waiting for you.

14. Everything in Yorkhill was quite compact. They had a canteen nearby. It doesn't sound important to other people but when you have a child on steroids, a canteen is very important. You need to be able to feed yourself too. The canteen was reasonable, not too expensive. If the children didn't like

what was for dinner or what was on the dinner trolley, they were given a wee yellow slip that they could take to the canteen and choose a meal.

15. There was a sense of community at the Yorkhill hospital. The Unit was called the Schiehallion Unit and we took the name over to the RHC with us. We didn't use ward numbers at Yorkhill.
16. The Schiehallion Unit was a sociable ward although we were aware the children were immunocompromised. They had wee cars and tractors for the children to play on. The children would toddle up and down the ward on a tractor. There was a great big play room too with lots of stuff going on in there. They used to invite external people in to do activities with the children. They had balloon makers, clowns, various different things going on. The children spent quite a lot of their time in the play room.
17. The children were encouraged to come out of their rooms and play. That's why there were activities put on in the playroom. It was a really sociable ward and had a strong sense of community.
18. There was a parent's kitchen at Yorkhill which was vital when you have a child on steroids. You could make a pot noodle, or heat something else up for them whenever they needed it. This was also where a lot of the parents supported each other too. It was a place you could cry, shout or get a cuddle if it was needed. There was a big family room too with couches, a television and books.

AMENITIES AT RHC

19. At the RHC blood test results took ages to come back, sometimes hours. You became 1 in 4000 patients compared to Yorkhill where you were 1 in 400

children. This was because the children's blood tests were then processed at the same place the adult patient's blood tests were processed.

20. I've mentioned the canteen at Yorkhill, there was nothing like that in the RHC. They had a canteen but it was in the adult hospital. You had to walk through the RHC then through the adult hospital to get to the canteen. If you're a [REDACTED] on your own, you're not going to leave your extremely sick child in the RHC to walk all the way to the canteen. The canteen was also very expensive. They did have a coffee shop in the RHC which was great for sandwiches and things but it was also expensive. It closed at 4 PM and wasn't open at weekends. There was a Marks and Spencer's there too but it was expensive.
21. The canteen doesn't seem like much but we were used to having a canteen, and relied on it. We missed having one, when we moved to the RHC. There were financial implications as everything was more expensive.
22. Having a child in treatment is expensive anyway. Running up and down to the hospital, fuelling your car, buying food as your child is on steroids and constantly eating, you've got yourself to feed, toys to buy to keep them amused. All these things matter while your child is going through treatment.
23. There was no sense of community at the RHC. The playroom the children had was tiny and could maybe only fit three children in it. My home bathroom is bigger. There were no external activities or people that came in to do things with the children. There were no cars or tractors. No children playing up and down the corridor. Children weren't encouraged to come out of their rooms and socialise. In fact, most of the children were locked in their room in isolation. They had nowhere to congregate. It was quite isolating for them and indeed the parents. They did have clown doctors and a balloon lady that came and made stuff outside your room window but it wasn't the same, especially if you'd been treated elsewhere like Yorkhill and had all these things previously. The play girls tried their best but there is only so much drawing and gluing

glittery things that children can do. [REDACTED]
[REDACTED]. The way the ward was shaped didn't exactly allow for socialising either.

24. Originally there wasn't a parent's kitchen on the plans for the RHC. Three of the parents at Yorkhill joined a committee to fight for one to be put in. We all knew we needed it but it wasn't included. The parents that fought for it went up to the new site before it was established and the building work was still being carried out on ward 2A to see the kitchen being installed. When we did move over to the RHC, the parent's kitchen was often closed or sections of it were closed. There would be a big yellow sticker on the door telling you it was closed or out of use but nobody ever told us why. We just accepted it was closed and didn't question it.

25. At the time, it did not seem like a big deal, the kitchen being closed, it was an inconvenience and there was a workaround; as long as [REDACTED] was okay, that was the main thing for me. It seemed petty to complain when your child is fighting for their life. However, these things were invaluable as that's where you got your support, from the other parents. You worried about how you were going to feed your child that was on steroids so it was important.

26. We were told there was a play park attached to one of the wards at the RHC as well as the play park further out nearer the car park. The one attached to the ward was never opened. They had one event in it but it never opened for the children to be able to play in. They had one event in it and the play leaders had been sent up beforehand to clean up all the pigeon droppings. That's the only event that I know of. The playground is something [REDACTED] would have used and we would have used as a family. There were wee gardens there too that the kids were meant to have access to but they never opened either. Children would've really benefitted from being out in the wee gardens or being able to use the park.

IMPACT OF MOVING TO RHC

27. There were a lot of changes when we moved the RHC.

28. It may not sound much but the loss of the services had a huge impact on us.

The increased time waiting on blood results, the lack of things for children to do, the financial implications of having to buy food when the parents kitchen wasn't available, the impact on [REDACTED] when the parents kitchen wasn't available and [REDACTED] wanted something to eat. All of these services were invaluable and there was a massive impact on [REDACTED] and us when we lost them.

29. When we were moving from Yorkhill, some of the staff moved to the new RHC with us but a lot of the staff left. I don't know the exact reasons why but I had heard the general consensus was that the RHC was very different to Yorkhill and had no sense of community, possibly due to the shape of the building or where it now was.

30. There was a huge impact on us when the staff left. We lost relationships which were really difficult to lose. Those staff members were our support. During one of the worst times in our lives, these staff members supported us and some became our friends. They had new staff members at the RHC but they didn't all have the same level of experience as some of the nurses who had left. We didn't have any 'go to' people. It also took time to build new relationships whereas at Yorkhill, all the staff knew [REDACTED] and they knew the family too. The fact you were moved to a different hospital where you didn't know your surroundings, you didn't know where you were going for treatment or what you were doing, losing those staff members had a huge impact on us. It made a difficult situation even harder.

31. Staff at the RHC rotated quite a lot too. You had the odd few that were always there but we were seen by different doctors and nurses quite a lot.

WATER EVENTS INVOLVING WATER SYSTEMS

Water Incidents in RHC

32. The first thing I noticed about the new hospital was that there were filters on the taps and the showers in 2015/2016 in ward 2A. We had just moved to this new, state of the art, all singing and all dancing hospital, so I didn't understand why the filters were needed.

33. There were signs up, advising the water was for washing only and not for drinking. I recall it was 2015 onwards. You were given bottled water for drinking by the staff. I wish I could remember the exact wording. [REDACTED] took a photo of it so I'll likely have it somewhere. We were washing our immunocompromised children in this water that you can't drink.

34. The showers were constantly flooding too. I had to get extra towels and fold them round the door so the water wouldn't get into the bedroom. There was never any plumber or staff who came to look at the showers after they flooded.

35. [REDACTED] hadn't been very well so we were in source but there were urine and stool samples in the bathroom when it flooded. I couldn't get out to take them anywhere and sometimes you could wait quite a while until a nurse was free to collect them. Sometimes they could sit for 24 hours.

36. You had to run the shower for five minutes before using it which was odd. I found that really difficult as if you have a child who's had an accident, you need to get them cleaned up. I didn't have the time to run the water for five

minutes before cleaning [REDACTED]. Even if [REDACTED] hadn't had an accident, the chemotherapy made [REDACTED] skin extra sensitive. [REDACTED] [REDACTED] was really anxious about getting showered and this would've been worse if I ran the shower for five minutes before using it.

37. At one point, we had to use bottled water on [REDACTED] to wash [REDACTED]. This was another level of drama. We were not told to use bottled water to wash [REDACTED], we decided to do this for personal reasons as we were aware of all the problems with the water and if it wasn't safe to drink, it wasn't safe to wash in.

Water Incidents: communication

38. Sometimes I raised concerns with staff. I would speak to nurses, auxiliary or the cleaner and show them something but they just used to agree with me and say, "I know, it's terrible". A lot of staff weren't happy at the new hospital but I don't know the exact reasons why. I didn't complain about the shower formally as in the grand scheme of things, the bathroom being flooded was an inconvenience, it was a pest. There were bigger things to worry about at the time, or so you thought. I didn't realise the implications regarding the water at the time. You just trusted people and the hospital as it was new and state of the art.

INFECTIONS

39. [REDACTED] had a number of infections when [REDACTED] was at the RHC. [REDACTED] had quite a lot of temperature spikes.
40. Usual protocol if a child spikes a temperature is to admit them to hospital where they have blood tests carried out and start them on IV antibiotics. These admissions could be varying lengths of time but the minimum is 48 hours to allow for blood results to come back.

41. One particular time that stands out is in [REDACTED] 2015. [REDACTED] is the type of child that just carries on with things, even with the steroids, losing [REDACTED] hair and going through chemotherapy, [REDACTED] was still up and about doing things. That [REDACTED] though, [REDACTED] was really ill. [REDACTED] had been complaining of severe headaches, he'd been vomiting and was clammy. Even the way [REDACTED] was acting was different. [REDACTED] just wanted to go to [REDACTED] bed. [REDACTED] was really, really ill. We phoned the hospital and we were told to take [REDACTED] up. They carried out a lumbar puncture, where they took fluid out of [REDACTED] Central Nervous System ("CNS") and tested it. We thought [REDACTED] was having a relapse. Even the nurses thought [REDACTED] was relapsing as they said to me, "if it is leukaemia again, you'll get through it again". I was relieved when staff told me it was a virus. I wanted it to be anything but leukaemia again.

42. I found a letter relating to the [REDACTED] 2015 illness in [REDACTED] medical notes. The letter was dated [REDACTED] 2015 and it was from Professor Gibson to [REDACTED] GP. It stated that [REDACTED] had a recent viral infection which caused the CNS lymphocytosis. There was a reference made to cells being found during the lumbar puncture but they didn't look like Leukaemia blasts.

43. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

44. As I've previously said, [REDACTED] had a number of infections but we were never told what they were or how [REDACTED] caught them.

45. Even though [REDACTED] was poorly in [REDACTED] [REDACTED] was only ever told it was a virus. Nobody ever told me what the virus was or what had caused it. The letter I found gave me more information than I received at the hospital. I pushed for an answer at the time. I pushed and pushed for answers but when I was told by staff it wasn't a relapse, I was relieved. I moved on.
46. [REDACTED] was in source quite a lot but we were never told exactly why. A sign used to appear on your door or staff would maybe say to you that you're sourced but no explanation was given. You just accepted it was part of treatment. [REDACTED] had diarrhoea quite a lot and he'd be in source for that but that was one of the side effects of chemotherapy. It impacted [REDACTED] bowel but we'd still be placed in source.
47. [REDACTED] cough during [REDACTED] treatment. [REDACTED] would be given simple linctus for it and sometimes placed in source. They never told me what was causing the cough.
48. The communication about [REDACTED] treatment wasn't that great and I found this frustrating. [REDACTED]
[REDACTED]. Maybe staff had a reason for not telling you too much at the time but the communication was terrible. You didn't know what to expect. You didn't know what was coming and you didn't know what was normal and what was abnormal. It was a very frustrating and difficult time.
49. I recall a point where I'd booked a holiday [REDACTED]
[REDACTED]
[REDACTED]. I was told I was not allowed to take [REDACTED] as he had a port and that was an infection risk. If he was to spike a temperature [REDACTED], [REDACTED]
[REDACTED]. It may sound like nothing but at the time, it was a really big thing for me.

50. There was a complete lack of communication. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]. Staff are very good at what they do but they forget that we're humans and parents and this is a very difficult time for us.

PREVENTATIVE ANTIBIOTICS

51. At the time, when [REDACTED] was undergoing treatment, he was on a number of antibiotics but I only found out [REDACTED] that [REDACTED] was on preventative ones. I'd given my solicitor some documents over the weekend and I was informed [REDACTED] had been on several, [REDACTED] when [REDACTED] was going through treatment at the RHC. I have no doubt that [REDACTED] would have been on the preventative antibiotics in [REDACTED] too.

OTHER ISSUES RELATING TO HOSPITAL CONSTRUCTION

Hospital build issues: impact of building issues

52. I do not remember much about building works going on at the hospital. I remember that the blinds on the windows didn't work and the rooms were very stuffy. There was no ventilation. We had fans in the rooms at one point to move the hot air around. I remember being able to use them and then not being able to use them. They had been supplied by the hospital but I remember them being taken away. Nobody explained why.

53. We did not have certainty about whether [REDACTED] would be admitted to Ward 2A if [REDACTED] had to come into the RHC, for example, with a temperature spike. The protocol at the beginning was that we would phone Day Care and they would tell us to come in and go to ward 2A. If [REDACTED] was admitted with a temperature spike, [REDACTED] was admitted for a minimum of 48 hours as that's how long it took to get the blood culture results back. However, they changed the protocol. I can't remember when the protocol changed. Nobody told me the protocol had changed or why. When I phoned after the protocol had changed, we would have to go in via Accident and Emergency then the Clinical Decision Unit. The department you were in would liaise with the Schiehallion Ward and tell you where you were going but sometimes this meant [REDACTED] was admitted on another ward as they said there were no rooms on the Schiehallion Ward. Sometimes we were not even told where you were going, you found out when you arrived at the ward you'd be in.
54. [REDACTED] could be placed in any ward where there was space. I noticed that there were rooms shut on ward 2A. All of the bone marrow transplant rooms were closed too with big yellow tape all over them. We were only told they were closed for cleaning. With these rooms being shut, there were less rooms on ward 2A, which is why [REDACTED] sometimes was admitted to other wards. This caused anxiety as you'd want to be on your own ward with your own team who knew [REDACTED] and knew what they were doing as they were all experts. However, the majority of time, you would be placed in another ward. It was horrendous.
55. Every ward was different too. In some, you could get a cup of tea or coffee but in the other wards, you couldn't. You would be isolated in a wee room waiting for your team to come and see you. That's another thing, if you weren't on ward 2A, you would be forgotten about. You had to phone the ward to remind them to send the doctor to you, so sometimes you wouldn't see the morning doctor until 6 PM. This was unsettling, frustrating and worrying. It caused a lot of anxiety.

56. When [REDACTED] was in a different ward the protocols didn't follow [REDACTED] Staff in the other wards didn't know how to deal with the grippers which are for the needles that go in and out of the port. Sometimes because it took so long for the staff in the Schiehallion Unit to come and see [REDACTED] treatment was delayed. This would have a big impact as you wouldn't know what was wrong but under protocol, [REDACTED] chemotherapy would have been stopped. If treatment was delayed, it meant a longer stay. It was very distressing and frustrating.

CLEANLINESS

57. The cleaner came in daily and cleaned the room. I was also cleaning the room on top of that with antibacterial wipes. We were never told to clean the room, we did it out of fear for our immunocompromised [REDACTED] and because we were observing the cleaners not deep cleaning the rooms. We were all ready for Covid long before it came as this is how lived before with having an immunocompromised child.

OVERALL EMOTIONAL IMPACT ON [REDACTED]

Overall emotional impact on [REDACTED]

58. [REDACTED] spent longer at the hospital due to infections or being in source and having [REDACTED] treatment delayed. [REDACTED] hated being stuck in that little room as [REDACTED] was so active and sociable. [REDACTED] had a lot of anger at that time and was lashing out. It's difficult to tell whether it was normal, a side effect of the treatment or the situation. Normal kids have tantrums too but there was a period of time when [REDACTED] behaviour was more difficult than normal. [REDACTED] was angry, upset and lashing out. [REDACTED] was quite down too when [REDACTED] was usually quite cheerful.

59. [REDACTED] had a lot of anxiety. It [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]. We have a great community here so we had a lot of support. [REDACTED] just catching up now.

60. [REDACTED] was not offered any education while [REDACTED] was in hospital for the entire time [REDACTED] was treated there. By law they only have to arrange for a teacher to come and educate a child if they are an in-patient over a certain amount of time, I am unsure how long that was. But in [REDACTED] we did not see a single teacher.

Overall emotional impact on witness

61. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

62. Being in source was difficult. I was trying to entertain a [REDACTED] child who is active and very difficult to entertain due to [REDACTED] lack of concentration which was a side effect of [REDACTED] treatment. It was a very depressing, lonely and isolating time. It felt as if [REDACTED] was constantly put in source without explanation which was upsetting. There were no protocols in place to help support [REDACTED] during [REDACTED] time in isolation but I don't know what else they could have done. [REDACTED] wasn't into arts and crafts which is what [REDACTED] was offered by the play

leaders. If the communication had been better my anxiety could have been reduced with understanding [REDACTED] situation. If the TVs in the room had been working at least, then that would have given [REDACTED] something, but even they were broken.

Overall emotional impact on other family members

63. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

COMMUNICATION GENERAL

64. We were never told why the play park attached to the ward was never opened. I'd heard it was because of the pigeons and their droppings. There were plenty of pigeons at the hospital but we didn't know the impact pigeon droppings could have at the time when we were at the hospital. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

65. [REDACTED]
[REDACTED] we trusted what staff were telling us. Don't get me wrong, the nurses and doctors saved [REDACTED] life and they were amazing. They helped us at that time and I feel for them too as they weren't given the information about the issues either. They didn't have the information to give to us so they were working under difficult circumstances as well as trying to care for us, [REDACTED] and all the other children and parents. I don't feel it's the fault of the

staff that we didn't get answers. I think it's a culture thing. It's a need to know basis.

COMPLAINTS

66. [REDACTED]
[REDACTED]. [REDACTED] was my main concern at the time and some of the things seemed so insignificant at the time when [REDACTED] was going through treatment. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

OVERSIGHT BOARD / CASE NOTE REVIEW / REPRESENTATIVE GROUPS

67. I've heard about the Oversight Board but don't know much about what they've been doing. I've only really heard about it in passing.

68. [REDACTED]
[REDACTED].

69. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]

[REDACTED]

70. [REDACTED]

71. [REDACTED]

CONCLUDING COMMENTS

72. The biggest impact for me overall is the lack of service, lack of community, being in source. By putting us in source constantly we were isolated from the parent community we had come to know. It made me feel they were trying to stop us speaking by isolating us all as well as trying to manage the constant infection outbreaks. While I was caring for [REDACTED], there were so many obstacles in my way. These things were not enabling me to care for [REDACTED] in the best possible way and give [REDACTED] the best possible care.

73. I have more trust in the staff than I do in the Health Board. I'm angry, disappointed and disgusted to be honest, that this has been allowed to happen at a Children's hospital. It should never have been built on sewerage

ground. I don't know why they moved it in the first place. They should have put money into Yorkhill and kept us there in my opinion. It's not the super state of the art hospital we were told it was going to be.

74. I don't know how faith is going to be restored in the hospital. The Public Inquiry is maybe the best way to do that and give us some answers as to what's happened, why it happened and how it was able to happen. Until we get these answers, I don't think any of us will feel reassured. I don't think the NHS standing up and saying, or lying again that's it's safe will help. That's all they've done is covered it up, passed it back. All they've done is lie.

75. I have received [REDACTED] medical records after requesting them. There is a huge pile of notes and none of them are in any order. I spent a weekend trying to sort them into some sort of order. [REDACTED]. I thought the books would be in order from [REDACTED] but they're not they're all over the place. I've tried to look at [REDACTED] admissions and infections to try and pull our certain dates but not all the notes are together. [REDACTED]
[REDACTED] I was expecting all the notes in the one place in some sort of order but no, there's bits about the same admission in all four books! There's no start, middle or end. It's a mess. I feel there's a lot missing too. The notes were sent to me like that from the records department at the hospital. Lots of us requested the notes for our children at the same time. It all comes back to the doubt we have now. I've lost trust in the hospital so I doubt [REDACTED] records will be right either. I don't know if everything will be here. I don't think they are. I know for a fact how many admissions [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED]. You trusted them at the time and didn't get any answers so I doubt [REDACTED] medical notes will be right. It's a horrible feeling, doubting everything and questioning everything.

76. [REDACTED]
[REDACTED]
[REDACTED]
[REDACTED].

77. [REDACTED]
[REDACTED]
[REDACTED]. Everything worries me about it. The pigeons, the ventilation, the water. It fills me full of worry and dread. The people that we trust to look after our children and to give us the correct information which allows us to make informed choices, I don't feel have done that. If I had all the information at the start, I could have made an informed choice and could have had [REDACTED] treated at another hospital, [REDACTED]. I could've decided whether I wanted [REDACTED] treated at a sick hospital a sick building because to me, that's what it is, it's a sick building. Why would I take my child somewhere sick?

78. The fact we weren't able to make an informed choice annoys me. I, [REDACTED] [REDACTED], kept taking [REDACTED] up there and putting [REDACTED] in a dangerous position but I didn't know that. Nobody told us.

79. 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.