Scottish Hospitals Inquiry

Witness Statement of

Matthew Smith

WITNESS DETAILS

1. My name is Matthew Smith. I was born on [redacted]. I am [redacted] years old. I am employed as [redacted].

2. I am the father of Sophia Evangeline Smith. Sophia's date of birth is [redacted] March 2017. Sophia died on [redacted] April 2017 aged [redacted] days old at the Neonatal Intensive Care Unit in the Queen Elizabeth University Hospital in Glasgow.

3. I live with my wife, Theresa Smith, and our children in [redacted]. [redacted].

OVERVIEW

4. My daughter is Sophia Evangeline Smith. Sophia was born at Paisley Maternity Unit on [redacted] March 2017. A few hours after she was born, Sophia was transferred to the Neonatal Intensive Care Unit in the Maternity Hospital in the Queen Elizabeth University Hospital (QEUH) in Glasgow. She was admitted as an in-patient and received treatment in the hospital up until the day she died on [redacted] April 2017.

5. During Sophia's admission, Theresa and I were with her every day. We stayed at Ronald McDonald House and we attended the hospital every day to sit with Sophia. We arrived at the hospital early morning, only leaving to get

something to eat and four hours sleep before we would head back over to see Sophia in the morning.

6. My mother-in-law and father-in-law looked after our other children at home in [redacted]. I can speak to the experience which Sophia and I had at the hospital.

7. There are some specific events that I would like to mention. Sophia contracted an infection which led to her death. The communication regarding Sophia's treatment, her cause of death and the communication after her death was severely lacking. I believe Sophia contracted the infection at the hospital, possibly due to lack of cleanliness or linked to the other issues relating to the hospital environment. I will come on to talk about these in more detail.

FAMILY BACKGROUND

8. I live with my wife, Theresa Smith and [redacted] children in [redacted]. [redacted] .

9. [redacted].

10. [redacted].

11. [redacted].

12. [redacted].

13. [redacted] .

14. [redacted].

15. [redacted].

16. [redacted].

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

Sophia's Birth: [redacted] March 2017

17. Throughout Theresa's pregnancy we'd had a couple of warning signs that things might not be 100% and we were sent for a couple of extra scans which didn't show anything. Theresa knows the staff at the hospital quite well, as you can imagine, so they know they can be straight with us. We were still slightly concerned so we spoke to Theresa's consultant, Dr Robins. He was very guarded along the way around some of the scans, especially regarding Sophia's heart shape, and he expressed a concern which is why we were sent for a further, more detailed scan at the QEUH, Foetal Heart department. When we went for the scan we were met by a couple of doctors. They carried out a test on Sophia and we were asked to wait outside. When they came out to speak to us, they said they couldn't see anything wrong. Although our minds were put at rest, it was still at the back of our minds. We felt Dr Robins, without saying it, was maybe indicating that there were some issues.

18. Sophia was born on, [redacted] March 2017 at Paisley Maternity Unit and we knew straight away there were some issues; When the baby is born, there's usually crying but that didn't happen with Sophia. She was obviously struggling to breathe a little bit at that time.

Sophia's Admission to QEUH: 1 April 2017

19. After Sophia had been delivered, it was communicated to us verbally that Sophia visibly looked like she might have Downs Syndrome. This was never an issue for us. We were more concerned about her breathing. Sophia was rushed away to Paisley's neonatal ward.

20. I was at the hospital with my mother-in-law. Theresa was in one ward and Sophia was in another. Theresa had desperately been trying to see Sophia though. After a couple of hours, my mother-in-law and I were told everything was going to be fine so we went home.

21. I received a phone call from Theresa in the middle of the night or very early morning, telling me that Sophia was being transferred in a special ambulance to the QEUH. I believe this was because the QEUH had more specialised machinery that doctors thought Sophia would require. She was then placed in a specially adapted ambulance which contained a lot of special equipment to keep a baby safe and there were paramedics going with her. I think Theresa got to see Sophia being placed in the ambulance but I can't remember 100%.

22. At this point, Theresa was still in a ward at Paisley and Sophia was being transferred to the QEUH. Theresa was wanting to travel with Sophia and knowing her, I think she would have kicked up a fuss and gotten her own way in the end. One way or another, Theresa left Paisley hospital and I picked her up. We went through to the QEUH and Sophia was in the Neonatal Intensive Care ward.

Sophia's treatment at QEUH: 1 April 2017 – 9 April 2017

23. We were told by a female doctor that Sophia was suffering from something called pulmonary hypertension. The doctor explained that Sophia's lungs were not inflating due to valves round her heart not working correctly or they hadn't opened at the time when Sophia was born. When babies are born, there's a reaction in the baby's body to open these valves and I believe this is why Sophia didn't cry when she was born. We were told that other than this, Sophia seemed to be alright and structurally sound.

24. We were told about a machine that doctors had been thinking about putting Sophia on. I believe it was called an ECMO machine if I remember correctly. The Doctor was going to assess her but she was in the ward with machinery in and around her. As Theresa had just given birth, she was obviously emotional. The news about Sophia had come as a massive shock to us.

25. We were still being told Sophia was potentially going on to that ECMO machine and throughout the first day that machine was lying around ready to be connected. It was explained this would give her more life support to enable them to treat their main concern, which was this pulmonary hypertension. We were encouraged throughout that day that Sophia had started fighting back; she never went on to the ECMO machine in those couple of days. We settled into the routine of staying with her for as long as we could and checking in to the Ronald McDonald house which they had arranged for us to stay in as obviously the travelling would have been an issue. Throughout those first few days we got to know the staff that were looking after Sophia, we got to understand the machinery and what it is was for and what the antibiotics were that she was on, what the level of oxygen support she was on and what the readings meant.

26. Sophia had one to one care with a staff nurse or a senior nurse and the way the room was set up was that there were incubator cots and at the top of each one of those, there was a nurse who was checking machinery, taking detailed notes, hourly oxygen saturation levels, when the antibiotics were being changed. On the whole, those staff were exceptional.

27. I think we were told about the extra support they were giving Sophia with her breathing. In their opinion, the pulmonary hypertension was meaning she wasn’t breathing properly so she needed support with breathing. I think we were shown the machine and we were shown the graph and the percentage. I think it might have been that doctor we met on those first couple of days that explained things to us but we were definitely aware it was support with

breathing that Sophia needed. I believe that when Sophia first arrived, she went on to antibiotics as well. I can't confirm this but it was more about the support with the breathing.

28. Sophia was connected up to a lot of machinery but nobody had really explained to us what it was all for. We just wanted Sophia to get the correct level of support at this time that she obviously required. We were then asked a couple of questions about getting Sophia christened. This highlighted the gravity of the situation we found ourselves in. We got in touch with a friend who's a local Priest and he was at the hospital within the hour. Sophia was quickly christened. We were then encouraged to go and get something to eat so we left the staff to it for a bit while we tried to rally ourselves and let friends and relatives know what was going on.

29. I think Sophia possibly had cannulas in her hands too. The nurses kept very detailed reports, almost like a timeline of their shifts, so there should be times recorded in Sophia's notes when the cannulas were changed. It was all very detailed.

30. From day two or three onwards the visible bank of machinery got less. When we first went in goodness knows how many machines were in and around her and making beeping noises. It got to the stage where there was just a couple of machines and there didn't seem to be as much intervention, lines etc.

31. Theresa was able to twice change Sophia's nappy. The way Sophia looked, combined with the feedback we were getting from the expert nurses, had led us to believe that she was making a steady progress. At one stage we were talking about Easter and having an Easter Egg hunt in the hospital grounds and we were told "No, no, no, I'm sure Sophia will be home at that point and you'll be able to do it in and around your house." In terms of what Sophia was being treated for at the start, we were getting to the end of that treatment and we were talking about potentially having her home within another couple of

weeks, potentially with oxygen through her nose with a cylinder, and a nasal tube. We were getting good feedback and were told she was getting better, she'll be better before you know it, and that's what we were focusing on.

32. We didn't discuss long term, what the issues would be or stuff like that. It was later confirmed that Sophia did have Trisomy 21 which is the medical term for Downs Syndrome but she was on the lower end of the spectrum, so there was no reason for us to have any major concerns other than the fact we were going to have a new child at home that may need some extra attention.

33. Every day we went up to the ward there was more positive news from the nurses looking after Sophia. The machines that Sophia was hooked up to seemed to be decreasing and the ECMO machine had been moved away. Sophia was progressing. They were decreasing the medication that she was on and the general consensus and, certainly the way that we were feeling, was that Sophia was going to be okay and she would be home at some stage.

34. We had a discussion with some of the senior nurses about when Sophia would be coming home. A young child in a wheelchair and a mother came in to the hospital to thank the staff for the care that the child had received and the child had a nasal oxygen. I remember Theresa asking, if that would be something that Sophia would have and the nurse said yes, the way Sophia was progressing they could probably let her home with minimal oxygen so she would get home. We were feeling really positive about it.

35. All along those days, it was pretty positive. There was one change, maybe day six or day seven, when we arrived at the ward, we met a nurse we had never met before. In our opinion, this nurse wasn't giving us as much feedback and we were slightly concerned. She wore a different uniform and we were told they were short staffed so the nurses we'd previously been exposed to, were now with different children. We were concerned at first as it wasn't someone we had met before but then we looked at it as a positive

because it meant the more senior nurse was with other children and we took that to mean that Sophia wasn't as much of a concern now.

36. Every day was pretty much ground-hog day, a bit of sleep, a bit of food and then up to the hospital to check on Sophia and look at her records. We got quite good at looking at her records. By this time, maybe day seven, eight or nine, Theresa had been encouraged to change Sophia's nappy under supervision and with gloves on, which was again a positive sign to us. This was Theresa's first interaction with Sophia. We couldn't touch her before. We were also encouraged by nursing staff to allow the other children to come up and at least see their sister. This would be on a one in one out basis so some of the older children that we thought could handle seeing the machinery could see her. This was a sign to us that it was positive and we didn't question it.

37. Everything was going well, Sophia was progressing, staff were talking about her coming home, and then the children, [redacted] could come up and get a photo with her and see her. The [redacted] and they were feeling our pain and they hadn't seen us for a while so my mother-in-law and father-in-law were bringing the kids up to the hospital. There's a play park at the hospital on the outside grounds and the kids would come up and we would have an hour or two with them throughout the day and [redacted] were allowed to come in and see Sophia. It was all positive. Yes she was ill, yes she was still in a hospital but she had gone from six to ten machines to just one or two machines and the oxygen support was very, very minimal. Then it all went rapidly down-hill.

Sophia and her family's surroundings: 1 April 2017 – 9 April 2017

38. The room Sophia was in was within the Neonatal ward. As you go in to the small ward, there's trough sinks, round the wall on the left hand side, soap dispensers and a cleanser. The sinks were the type you see in surgery that

you could do with your elbows as opposed to taps. There were about 6 cots in the room including Sophia's. At the end of each cot/incubator there was the work station where the nurse predominately stood but I think they had some sort of stools as well. There were milk fridges and general stuff over that side too. The ward was quite light; there were windows at the back end of it. Out of that room there was an area where the consultants would sit and I think there was a glass partition where the consultants could see in to the ward. The partition faced out the way as you came in to the ward. There were coat stands, where you could hang your jacket. They didn't encourage you to take jackets into the ward. That was explained to you on the first day on the ward so you could hang your stuff up there and then there were another one or two wards like that. Then there was a back ward that had a parents' room, which was a very small room with a kettle and a fridge in it I think. There were a couple of other subsequent rooms where we would sit on occasions, especially on the last day or two.

39. I think because a lot of the babies within that ward were in incubators, it was an exceptionally warm environment. It was temperature controlled but it was always very warm, even if you went in at night, it was always just a t-shirt you would have on as it was exceptionally hot. The whole of that area is warm but I presume it's for a reason. Most of the babies are undressed and just in nappies because they're in the incubators.

40. Service rooms and parent rooms are very small, there's not a lot of space in them. There's not a lot of amenities, bearing in mind some of the parents we met had been there for months and it was etched on their faces.

41. The room through the back of the ward always seemed to be clean although you never saw any cleaners going around. There was always soap in the dispensers at the sinks. I think on the first couple of days, we were all shown how to wash our hands but you weren't told why. Staff told us they would like us to leave outdoor clothes outside the ward and showed us where the sinks

for washing our hands were. There were other parents and visitors that came into the ward with their outside clothing on or without washing their hands and they were never challenged. Whether or not it was a nurses duty to challenge people or not, I don't know. I don't think any hospital would be a nice environment but it wasn't a pleasurable environment to spend a lot of time, uncomfortable as well.

42. There was a room on the ward where parents could stay overnight but we were down at Ronald McDonald House. It was quite a long walk from the ward Sophia was on to Ronald McDonald House. When you're having only four hours sleep and only taking a break to get something to eat during the day, you didn't want to spend 25 minutes walking to and from the ward. It ate into your day. The room we ended up in whilst Sophia was going on the ECMO machine had plastic chairs. It's a simple hospital room but at the time, it's adequate when you're focused on other things.

43. There was a wee kitchen too. I think we only went in to boil water for tea and coffee. We used the fridge to keep bottles of water in which we'd bought from Marks and Spencers. There were other bottles of water in the fridge too that I think we could have used. We did all out cooking or made sandwiches at Ronald McDonald House or ate in the main hospital canteen.

44. I believe there were a couple of occasions where the lights all went off and you could hear the machines bleeping and something kicked in quite quickly. I remember Theresa raising a concern and asking what was going on. She was told by one of the staff, "Don't worry, the back-up generator will kick in", but there were still several seconds where machines were making some funny noises which would have been quite worrying.

Sophia's treatment at QEUH: 9 April 2017 – [redacted] April 2017

45. Theresa was slightly concerned about Sophia's demeanour and colouring so she raised her concerns and a consultant, [redacted] came to examine Sophia. He said he would need to perform a scope on her to have a look down her windpipe and we were getting more and more concerned. We were asked to leave – we'd left when he was doing this bedside procedure. After doing the procedure, he told us he could see there was blood on Sophia's oesophagus and there must be a lot of blood. He showed us a scan that they did of her lungs and he could pin point that one of her lungs had collapsed.

46. We were starting to get really, really concerned and it was at this point that the machinery around Sophia and the medication she was put on started it increase rapidly again. That's when we knew we were in a different sort of level to where we had been. I think this was around day nine or ten, possibly 10 April 2017 but I can't confirm the exact date.

47. The deterioration was quite rapid. We had returned to Ronald McDonald House as we had [redacted]children sleeping over with us as that's where we had been staying. I think we were sleeping and the phone rang. It was the first time they had called us through the night when we weren't on the ward. There was a staff manager, nurses and a senior staff nurse on the ward. I think it was the senior staff nurse that called us. She said we'd better get up quickly as they were now talking about Sophia going on to ECMO which was this machine that had been there on day one and two.

48. We got up there as quickly as we could. As we went in, there seemed to be a team of doctors and people that we had never really met before. One was Mr Davis who we had seen before, he was the ECMO machine specialist. I'm not sure if he designed the ECMO machine or not but he was the main man around this machine. Mr Davis seemed to be leading this conversation with a

group of consultants. The conversation seemed to go for on a while when we were at Sophia's bed, panicking about what was going on with Sophia.

49. By early morning we'd had some discussions with various consultants who were around, and it had taken quite a while to get Sophia on to the ECMO machine. There had obviously been some discussion about the merits of putting Sophia on to this machine and obviously as parents we wouldn't want her to be harmed any more but at the same time, it was our duty to make sure she was getting the best care. We thought the ECMO machine was obviously the best course of action.

50. The ECMO machine was big with a lot of hoses or tube type things. The way I think it was explained, was that it basically did the work of pumping the blood around the body, taking the work off the lungs and the heart. I might be wrong in that but I seem to recall, it was doing the work of the organs which were obviously at this stage, failing.

51. Once Sophia was on the machine, we were allowed in to see her but it was plainly obvious by her physical state, that things were not good. It looked as if there was bruising on her lower body and it was black and discoloured because she wasn't getting enough oxygenated blood to her extremities as it was all getting sent to her brain. Her skin had darkened towards the bottom of her body, she wasn't the sort of rosy, pinkie colour that she had been. The oxygen levels had gone up but the increased levels obviously weren't working. Nobody really knew why it wasn't working until later on when we were able to establish what the issue was.

52. We didn't understand what was going on and to be perfectly honest, I don't think the doctors did at that point either. They didn't tell us what they were doing or the reasons why. I think it was about buying time.

53. We were then in the family room through the back of Sophia's ward when Dr Coutts came in and had a couple of conversations with us along the lines of, she's not doing well how long do you want to keep her on this machine, we don't know what's going on. I was more concerned about what Sophia was feeling. They told me that in their experience she wasn't feeling any pain but her major organs were starting to fail. I was probably of the opinion at that point that Sophia had given it a great fight and things were against us now and potentially having all these machines was not going to give us the result we were hoping for.

54. We were having a conversation about what we were going to do and then a nurse or doctor came in and said, "You need to come now". We went back in the room and it had been cleared out of the other parents. Sophia was obviously failing quite badly and dying in front of our eyes. The nurses were as visibly upset as we were. Sophia was taken out the cot, the machines were switched off and she died in Theresa's arms with me and Theresa's mother there.

55. That was the first time Theresa had held Sophia and she passed in her arms within a matter of minutes of the machines being switched off. They checked there was no heartbeat and pronounced her dead.

Sophia's family's experience at QEUH: 9 April 2017 – [redacted] April 2017

56. Sophia died on the [redacted] April 2017. I think we returned the next day and we were taken into a room, a darkened room, which had twinkly fairy lights or something like that and we were told we could hold Sophia and take some pictures. That room is something that will haunt me for the rest of my life I could hear a mechanical fridge freezer type thing being opened. I remember Theresa looking at me and we both knew exactly what it was. Sophia was brought out and presented to us with a bloody great sticker right across her front on top of what she was wearing. It was obviously the identification of

Sophia. It had her CHI number on it and something else. The only way to describe it was like a slab of meat in the mortuary, you know when you buy a slab of meat and it’s got whatever stamp on it to identify it.

57. That was it and we spent a couple of hours there, took some photos of Sophia and cleared out our room in Ronald McDonald House. Then I engaged with funeral directors who were absolutely brilliant. Very professional and did everything that was asked of them and more. They had gone up and picked Sophia up from the hospital and then we went to see her in the funeral home. I didn’t go at first, as I just couldn’t handle it.

Events immediately after Sophia’s death

58. Theresa was taken in by the Funeral Director. I think his name was, Kenneth. He raised some concerns with Theresa about Sophia’s appearance and whether or not it was a good idea for Theresa to continue to go and see her. [redacted]

Then it was the funeral and waiting on the reports.

ISSUES RELATING TO HOSPITAL CONSTRUCTION

59. One of the first things I remember about the hospital before it was exposed in the media or before people started discussing it, was the smell. You could smell it outside and in some inside areas of the hospital. On some days,

especially on warm days, there was a vile, almost sick making, smell. You probably didn't realise it at the time but obviously now it's at the forefront of everyone's attention. The smell was everywhere you were in the hospital. If you were in the downstairs you could smell it from the entrance and all the way in.

60. The pigeon droppings all around were never cleared. Being non-smokers, the fact the smoking all went on at the front of the hospital was not good. We saw people going around picking rubbish up but it wasn't a particularly clean outside space. It was mainly concrete.

61. Some of the toilets that you used downstairs on the way up to the ward, were all always a bit dirty and stuff like that. Some of the things, that these other parents were discussing, such as the smell and the pigeon droppings, we could certainly have empathy with them.

62. Obviously on our first day on the ward, we weren't taking in enough but there certainly wasn't enough education about hand washing. Look where we are with Covid just now. There wasn't enough education or signage I believe. As you walked in the ward, there was a board showing percentages, charts and arrows pointing at basically how good they are in terms of infections and stuff like that. That was never explained to us, it was never explained to us how serious infections could be for children. As I said, the majority of nurses we saw would come in, constantly washing their hands. There were times though, breaks for example, where the nurses would be going between one or more children and then to different areas. Then nurses all had work stations and they had those sort of alcohol type wipes. If a machine alarm had went off on another child and her nurse was on a tea break, one of the other nurses would see to them and then come back to the other one without washing their hands or using gloves. We now know more than ever how infections can be passed that way. The consultants, very rarely when they came in, did you see them washing their hands.

63. The hospital is so big, everywhere takes so long to get to. You've got to go through so many doors, so many passageways and in so many lifts. There's doors that should be open for ease of access that aren't open so you have to go all the way around the houses.

64. I've already mentioned the environment that the hospital sits in terms of the sewage works and the smell from it. The amount of traffic in the place as well and the masses and masses of car parking, yet the parking still isn't adequate. There was simply not enough parking. I'm not an architect but I've never understood the main atrium or whatever it's meant to be with all the glass. When a helicopter lands on the building roof, the whole place shakes and you can hear it but you can't hear yourself think. The general upkeep of the front of the building especially with people dropping cigarettes, overflowing bins and pigeons isn't good.

OVERALL EMOTIONAL IMPACT ON SOPHIA'S FAMILY

Overall emotional impact on witness

65. It's impacted me greatly and to be honest, for the first time in my adult life, I've had to seek some help. I'm currently not at work and seeing counsellors. At the time I suppose your head is down and you're just battling through it for your other children but for the last 6 months, since [redacted] was born, it has impacted me greatly.

66. With the greatest of respect, going through what we're going through now, having to relive it, is impacting me. We've lived it every day for the last four years, and we're now living it again and I mean really living it again, trying to come across the best we can to get the answers that we deserve.

67. I found [redacted] being in hospital, for 51 days over Christmas difficult. Although

[redacted] was never at any stage touch and go and there were no major issues other than the fact she was premature, she was in an environment where potentially she was at risk in our eyes. I still have that fear whenever we go up to that hospital. 51 days in the hospital and I felt it was a bit like Russian roulette in terms of the issues and that has impacted my mental health quite severely and it's not got much better recently.

Overall emotional impact on the family

68. After Sophia died, we went home after a couple of hours or so. [redacted].

69. As a father, it's my job to protect my wife and kids to the best of my ability. The effect on my wife has been immense. Sophia is still as important as the rest of our children and our family. Theresa, thankfully, has stopped going up to see Sophia's grave every day but she's still there two or three times a week. We try and take the children up once a week, they all know who Sophia is, we've never hid it from them. There's pictures of Sophia in all of our rooms, they all know about her. They'll all grow up with experience of losing a sibling which is a sin to them.

70. [redacted].

71. [redacted]. Only time will tell. They'll sometimes discuss it and they know what we're doing on calls like this and the other stuff that's been going on and they'll ask, is that you still fighting for Sophia? It pulls as your heart strings. As I say, it's devastated my wife. I probably engrossed myself too much in work for those two or three years and I'm paying the penalty now as my mental health is now suffering.

COMMUNICATION

Communication up until Sophia's death

72. Sophia initially was being cared for by Senior Staff Nurses. They kept us up to date with how Sophia was progressing, what the improvements were and what we should be looking for. We were greatly encouraged by the feedback we were getting. Communication was mainly done through the nurses that were looking after Sophia. We seemed to have the same couple of nurses dayshift/nightshift for a few days then they would come to the end of their shift and it would change. Most of them were very good and engaging and were communicating what they were looking for. They were passing on the fact that Sophia was improving. We had a couple of conversations with the consultants who were on during those days too and all the feedback we were getting was that she was doing good, she was improving and, the oxygen support levels that she required were decreasing. The consultant on the first few days didn't really engage with us very much.

73. I certainly remember having some conversations with Dr Patel, I think he was the doctor that was on the ward. He explained in great detail about the pulmonary hypertension and he also told us that Sophia was walking out of the woods. He described that she was out of the danger of death and we were thinking, great, and feeling a lot more positive about what had been a horrific situation.

74. Through-out those first days we were eighteen or nineteen hours a day at the hospital, only nipping away for something to eat and then back to Ronald McDonald House. We were well received by the nurses when we came back at different times. The majority of the nurses were phenomenal and told us everything we needed to do, they gave us direct dials for phone numbers so that we could phone up before we went over to check up on how she was doing.

75. We weren't told about any infections when Sophia was ill. We were under the impression that the doctors didn't know what the deterioration was and they were going through a series of checks to find out. We could see by Sophia's demeanour and her skin colour that it was something severe but at no stage did they tell us what it could be.

76. The majority of the communication with the frontline staff, the nurses looking after Sophia was very good. They were always very amenable and they were always happy to explain the machines. We wanted to know everything that was going on and they were happy to share information. Sophia was there for eleven days so that would break down into twenty-two shifts. I would say that eighteen or nineteen of the shifts were good communication, two or three were poor because the nurses didn't communicate, didn't tell us what was going on and didn't like us asking questions. The majority, especially the nurses in the first few days who we took to be more senior, were very, very good and as I say amenable and empathic, giving us good explanations of things.

77. Consultants were a bit hit and miss. I knew they were busy looking over multiple cases but as a parent your focus is on one individual and you're looking for the best of these consultants' attention but you didn't always get that. Some of them were down right ignorant and you felt that you were being a bit of a pain. Others were not too bad but you had to push them. That continued if you look at aftercare as well.

Communication: after Sophia's death

78. One of my abiding memories was that within a short time after Sophia had passed, we were in a room. Theresa's father had arrived at this point and we were obviously explaining what's going on as best we could and [redacted] came

in. We were sitting on the seats and I remember him squatting down to our level. He sympathised and then said he was sorry but there was some paper work that needed to be completed. Words failed me at that time; I understand there's a process and everything but it was within a short time after Sophia's death. I think Theresa's father questioned why this had to be done so soon and [redacted] explained he needed to issue a death certificate and that we would need the certificate so we could start getting organised for burials and stuff. He also told us that he had had a conversation with the Procurator Fiscal. I presumed that was part of the process in issuing a certificate and we were told that the cause of death would go down as Trisomy 21, which is the term for Downs Syndrome. This was obviously a shock for us, in our opinion, although Sophia had Downs Syndrome, she hadn't died from it. I'm not sure how it came about but we started discussing a post mortem. I think our opinion at that time was that we wanted to know how Sophia had died but we needed answers other than Trisomy 21 as cause of death. Other than seeing an unwell child get progressively better then suddenly deteriorating, I think we knew that something else would be the cause. Obviously we were looking for learnings for ourselves and any other families, and also that if there was anything genetic that we would be passing it on so we explained that we would like a PM. Then I think we were presented with a form which authorises a post mortem and I know it was me that signed it.

79.

[redacted]

80. Theresa phoned numerous occasions [redacted] to see what was going, on following the post mortem and it took weeks.

[redacted]

I think it was the June that a meeting had been arranged. Theresa and I went to the hospital for the meeting. [redacted], [redacted],

[redacted]

During this meeting, we were told that Sophia had something called MSSA PVL. Then it was explained that this was a very toxic form of MRSA. We asked if it could have been picked up in the Neonatal ward and we were informed that they didn't know where she got the infection from.

[redacted]

We certainly pushed that up until Sophia got this infection, she was progressing well so we couldn't understand why this happened to her.

[redacted]

81. We were concerned about what we had been told so we had a discussion with Mr Davis, the ECMO machine specialist. Sophia hadn't been doing very well on the ECMO machine, and the deterioration was very rapid when she was on it. Mr Davis he told us, that when he opened up Sophia's jugular, which is where this machine must be connected to, that he could see from her inside organs it was very white instead of pink/red and he couldn't actually see where he was going because of how badly the infection had taken hold of her body. I think it was said to us that it was probably too late by the time she

went on the ECMO machine to save her. Now, whether that was the delay on putting her on the ECMO machine or if the infection had been missed for a time, we don’t know.

82. [redacted]

83. [redacted]

84. [redacted]

85. [redacted]

86. The doctors still didn’t understand it from a parent’s point of view. All we’ve ever looked for is the truth and the answers. If doctors don’t know the answers, they should tell us they don’t know and go and find out. Don’t just keep flannelling us and telling us about luck. Forward us the answer and if they can’t or don’t know the answer, at least go and find out as much as they can. We’ve never ever had the feeling from the doctors that they’ve tried to find out answers. We’ve never felt confident in getting the answers from anyone that we’ve spoken to, consultant or otherwise.

87. I suppose at that point we were starting to see this general disregard for parents and loved ones of a deceased patient. We never should have had to fight as hard as we did for any answers or anything from them but it was always us that had to chase and ask questions. I appreciate that front line consultants are busy people and there to deal with patients. Consultants may be too busy or may not have the skills to deal with the other side of the job, the liaising with parents and following through on reports, but we were not given an alternative other than to deal with this person. It always struck me as very strange that there wasn’t a support network that would kick in and would take some of the pressure off the parents and the consultants. Obviously the consultant would have to be the one to give the answers but he didn’t have to do all the fact finding or answer our emails. There should have been someone there to tell him, the Smiths would like a meeting with you, give him a list of what we wanted to know and ask if he was in a position to answer our questions, if not, ask if there’s another team that can answer us. That was never done and as I say, these are supposed experts in paediatric care. Maybe dealing with parents isn’t their strong point so there should have been people to take that off them after the event.

88. The aftercare was exceptionally poor and I think that will be a common theme that will potentially come out of this inquiry. Maybe these consultants are not the best people to be following through on this. Maybe it needs to be a person that is more independent.

[redacted]

We've been through all of that and still didn't feel as if we had closure, we still didn't have any answers and we can't move on. We've done the best for Sophia's legacy that we can but we've never had that closure. Never had that feeling.

89. In 2019, Theresa emailed Jeane Freeman's office. I think she had seen her on the television as the Health Secretary at that time. Jeane Freeman's office arranged for us to go up to the hospital and have a meeting with Dr Coutts and I think there was another Senior Nurse there, Rogers, I think her name was.

90. We were asked by Jeane Freeman's office to submit questions in advance that we would like to be answered.

91. We explained that we were still looking for the answers as to how, in a sterile ward, this infection can be caught and why. Why it was missed. If I think back, it had been missed.

[redacted]

We weren't happy that the progression she had made since birth, had been lost by such a rapid deterioration.

92. We asked if we should bring representation to the meeting organised by Jeane Freeman's office and we were told it wasn't necessary. We were told

they would send someone from an organisation called PASS, and they would come along and take notes and details so there was a record of it. I don’t really know who PASS are or even what the name stands for but I think they’re a ‘go between’ for the hospital and parents.

93. The only thing that came out of the meeting organised by Jeane Freeman’s office, was that they kept saying everything was done in good practice. One sort of slip from them was that the arterial line could have been a possible entry for the infection. We had suspected the infection came from the arterial line as she had no other breaks in her skin. Sophia had only ever been in two hospitals so it was laughable some of the statements they were coming out with about how she could have caught it, it wasn’t as if she was running around in a park or anything. We were still banging our heads against a brick wall. The meeting didn’t really get us anywhere with that. The notes from this meeting didn’t represent the tone either. We were talked to almost as if we were naughty school children and we were being a bit of a pain in how we were progressing things.

94. After the meeting that Jeane Freeman’s office had organised, there was a bit of email communication between us and her office. We thanked her very much but we still didn’t have the answers we were looking for. I think it was maybe at this point that we started looking into legal representation.

95. [redacted]

[redacted]

COMPLAINTS

96. Later on in 2017, Theresa wrote a strongly worded letter to the Public Services Ombudsman and we detailed some of the concerns we had around Sophia's case and how we had been treated. The Ombudsman had an SLA of maybe 20-25 days and they exceeded that. We got a letter if I recall correctly, saying they had staff shortages and apologising for not coming back to us sooner. This set the tone for how things progressed. I think we had a further meeting at the hospital or it might have been after that when we eventually got

the results from our complaint. We were told they were not upholding the results from our complaint, everything was fine. There were inaccuracies with it and it gave us the impression that Sophia didn't matter to anyone and that the hospital weren't taking our complaint or concerns seriously.

97. We're still trying to get to the bottom of everything that went on with Sophia regarding the infection she caught and how it was caught. To me though, the total disregard of grieving parents, was just awful. To be perfectly honest, if you make a complaint in a supermarket about not getting something, they deal with it in a more professional manner than the hospital ever did. We should never had had to continue fighting and emailing and phoning.

CONCLUDING COMMENTS

98. When the reports started appearing in the news about the hospital, we realised that we weren't mad parents that but we were on the cusp of something that could potentially give us some insight into Sophia's case. The concerns have always been based around the main hospital and specifically the cancer ward but in our time there some of the things they were discussing, we could sympathise with. We saw some of those things when we were there: the smell mentioned was present when we were there too and we witnessed the pigeon droppings. At that stage we never thought that Sophia would be anything to do with pigeon droppings but some of what they were talking about, we can 100% back the other parents up and we felt the same. It was interesting watching them progress on the news. It was obvious it was big news and obviously it affected us too; we wanted Sophia's case to be looked at. We wanted some of this exposure and we felt that Sophia was maybe getting left behind a little bit. We never courted the press at any point although we had been asked. We reached out to a legal professional we knew, lawyers and obviously news organisations, primarily as we felt as we were getting nowhere. We certainly had empathy for the parents that did come on the

news and speak because what they were talking about were things that we could understand and had lived through as well.

99. [redacted]. I think genuinely, the staff are exceptional; everyone I've had dealings with from the staff point of view, the nurses, all are trying their best. I think the hospital is let down by: organisation; by structure; potentially water; and the other issues. It will all come out in the wash eventually but I think the people there are generally good people. The hospital is lacking senior leadership potentially in terms of people coming out and saying, "we've got an issue and this is what we're going to do about it". I think they'll rule out people that are trying to whitewash certain things or that don't take an interest in the aftercare or supporting people, but the hospital itself? [redacted].
I think it must be having a detrimental effect on the staff as well. I think they want to do a good job and they're trying to do a good job but I believe they're getting let down, maybe by more senior people or by politicians. There's a culture of secrecy and non-transparency that comes out of the hospital.

100. We've given witness statements to the police. We had quite a detailed six week period where we were up and down to a police station on the outskirts of Glasgow airport. This was over year ago, at the start of Covid, and as far as we are aware, it is still ongoing but we haven't had any updates from the police directly.

101. We've had contact with the Procurator Fiscal. We had an introductory zoom call with them and they have confirmed they have our statements. We don't know what they are planning to do next.

102. I think Sophia's infection came from a dirty piece of equipment or an unsterile piece of equipment in to her arterial line. The toxicity of the infection and the rapid decline means that something was amiss. I hope and pray at some stage we get that answer.

103. It has been a horrific experience. It’s been life defining. I am exasperated by all the things I have mentioned: poor communication; lack of empathy; feedback being atrocious; support.

104. 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.