

## Scottish Hospitals Inquiry

Witness Statement of

**Molly Cuddihy**

### WITNESS DETAILS

1. My name is Molly Heron Cuddihy. I was born on [REDACTED]. I am 19 years old. I am a student at [REDACTED].
2. I live with my parents and my brother in [REDACTED].

### OVERVIEW

3. I was diagnosed with metastatic Ewing's sarcoma with a primary site in my 11<sup>th</sup> rib. At the time of my diagnosis, I was 15 years old and was in 4<sup>th</sup> year at high school. I was studying for my National 5 exams.
4. I was a patient and received treatment at the Royal Hospital for Children in Glasgow ("RHC") and the Queen Elizabeth University Hospital in Glasgow ("QEUH") between January 2018 to 2020.
5. I now receive most of my treatment at the Beatson Hospital in Glasgow, although I am occasionally required to attend the QEUH.
6. I was treated in wards 2A and 2B of the RHC which is known as the Schiehallion Unit. The Schiehallion Unit treats children with all types of cancer. I also spent time in other wards on the RHC, namely 1E, 3A, 3C and the Paediatric intensive Care Unit ("PICU"). Following the closure of the Schiehallion Unit in 2018, I was treated in ward 6A of the QEUH. I can speak to the experience that I had on these wards.

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7. There are some specific events that I would like to mention. I contracted mycobacterium chelonae in May 2018 when in ward 2A and I contracted an acne infection in February 2019. I was prescribed preventative medication which I believe was connected to issues with the hospital environment. There were all sorts of issues with the hospital throughout my time there which, in my view, impacted on my treatment and on my experience. I will talk about these in more detail.

### **FAMILY BACKGROUND**

8. I live with my father, John, my mother, [REDACTED] and my brother, [REDACTED]. [REDACTED] is my older brother, he is [REDACTED] years old. He has moved back home with us after finishing university where he studied [REDACTED]. I am really close to my brother. We get on well, so it is nice having him home as much as I complain. We're very different, he's very sporty and I don't go near anything that involves any physical activity. He was a bit disappointed in me for that side of things! I have a good relationship with all my family.

### **WITNESS BACKGROUND**

9. I am a studying physiology at the [REDACTED]. I am in my [REDACTED] year and have just finished my exams, I spent the last year studying biology and chemistry and an elective in maths. I did well actually, considering I was doing my lectures from home for a year. Hopefully, I won't be doing that for too much longer.
10. I enjoy my studies and it has been really important to me that I do well. That's always been my biggest thing. I have a big ambition, I've always wanted to be a doctor. It has been something that I've wanted to pursue. I've never felt forced to do it, and it is certainly what helped me throughout being in the hospital. It was something else for me to focus on. Once I finish my degree in physiology I hope that I can go straight into a degree in medicine.

11. Outside of studying, I am really into music. I have played the piano since I was about three or four years old. I started off young because my brother used to get piano lessons and I had to get piano lessons too. Out of the two of us, I was the one that stuck it out. I enjoy singing as well. The two always came hand in hand throughout school, and that was my biggest hobby outside of my studies. I love going to concerts, me and my pals go together. One of the biggest things I've missed is going to concerts, I've just not been able to do so physically. In addition, being that close to people with bugs, and in that kind of environment, was not the safest thing for me when going through treatment.
12. I was fortunate and actually sang with Paolo Nutini who's been my favourite since I was a kid. It was through the Make A Wish charity and this was my wish. I grew up listening to him, so that was incredible. I went down to London and sang with him in a recording studio.
13. I like a range of music, and don't tend to stick to one genre. I like a lot of older music, my dad will tell me about songs he used to listen to and then we listen together. The Killers are one of my favourite bands, I went to see them at TRNSMT. I love Sam Fender and even musicals.
14. I am on the committee of the Anthony Nolan branch at the [REDACTED]. The charity have student-run branches within some major universities. Students tend to be a group that they target to seek donors for stem cells. During my treatment, I saw a lot of people who needed transplants on the ward. I was fortunate that I had my own stem cells for transplant, but a lot of my friends weren't that lucky. I began as one of the donor recruitment coordinators, encouraging people to join the stem cell register. I'm moving on to help with the social media campaigns. For example, making sure that we have frequently answered questions available on social media platforms; you'd be hard pushed to find a student that doesn't use social media. It's one of the best spaces to put information out there, it is easily accessible and it might catch someone's attention.

15. I enjoy spending time with my friends and I'm a big reader. Now that university is finished for the summer, I enjoy having time to read.

### **EVERY THANK YOU COUNTS**

16. I founded a charity called Every Thank You Counts along with my friend, [REDACTED]. I met [REDACTED] on the ward; we both were in the Teenage Cancer Trust ("TCT") part of the Schiehallion unit in the RHC. [REDACTED] and I were fortunate in that we had access to the social room for the teenagers on the ward, it was provided by the TCT. That was where we met and it was where we spent time together; it was what brought us through the experience of treatment.
17. We did notice was that whilst the youngest kids in the Schiehallion Unit had the playroom and teenagers had the TCT common room, there was a gap in the provision for the eight to twelve year old group. There was one particular story that kind of stood out for us. A boy came in to the TCT common room; he was a patient and he didn't look very well. He had asked me and [REDACTED] how to use the PlayStation. We set it up for him and he began to play with it. You could see his mood lift and he looked like a very different boy; he didn't look as sick anymore. One of the nurses came into the room as a he was not a teenager. We hadn't realised that he was under 13 years old, and so unfortunately he couldn't stay. It was a horrible job for the nurse; no one likes to do that. As a result of that event [REDACTED] and I wanted to do something; we wanted to change that and provide something for the kids aged eight to twelve years old.
18. We started off with the idea of a ball to fundraise and the idea grew from there. Originally we thought if we could raise £50,000, that would be incredible. Today we're sitting at well over £300,000. The ball was held in October 2019 and we raised £250,000 on the night. We're really proud of ourselves for that.
19. We have used the money raised to provide a room in ward 2A of the Schiehallion unit in the RHC. Work on the room is almost finished and it was

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carried out whilst the ward has been getting rebuilt. It has been one of the only good things about ward 2A getting rebuilt; we've been able to get work done to create this new room. We hope that the room will be finished in July 2021, and I understand that the Ward 2A might open in September 2021.

20. It will generally be for eight to twelve year olds, but we're leaving it to the discretion of the staff within the ward. It is for anyone that is in that middle age that's too young for the teenagers' room and too old for the playroom. We want kids to use this space, we do not want to cut it off and then there be another gap in provision. If we were to do that we would never stop trying to build rooms for kids, so we're not keeping it strictly within an age limit in that sense. We are keeping the "ETYC" name, so that it's the "Eight to Twelve Years Club" kind-of-thing, whilst it is "Every Thank You Counts" at the same time. Generally it will be for that age group, but there may be some exceptions.
21. As regards the facilities in the room, one of the main things that the families have asked for is somewhere that they can go and watch movies together. It is important. Whilst we have the cinema within the hospital, patients are not allowed to go if they're on a drip, and that is the majority of Schiehallion patients. You'd be very hard pushed to try and find someone that is not on a drip, therefore getting to the cinema is actually quite difficult. Being able to have a movie night that is not on a tiny iPad would make all the difference for families. It would give them something to do and something that they're used to doing together. They can all sit in big comfy seats. The kids can meet each other there and watch TV and movies together. We'd also like to have gaming consoles: the PlayStation, Switches or whatever everyone plays now.
22. We'd also like to provide board games or Lego; things that would be a comfort to people. We've planned a reading nook. People might like to use their iPads there. I really like my books, but I know that a lot of people probably won't always want to read.

23. Personally, the main thing for me is to provide a table. During my treatment, that was something that made a big difference to me. Because of the medication and treatment, I didn't want to eat but I was adamant I was not going to have a feeding tube. Having somewhere to sit down and eat was important to me. It broke up my day and I did not want to eat in my bed. Being able to sit and have a cup of tea or one thing to eat, even if it's a packet of crisps; it was something. It is the one thing that you don't realise that you're going to miss; sitting down together as a family, being able to sit down with other people or with siblings.
24. The space we have for the room is not the biggest space, it is not as big as TCT common room. We think that we've got it planned out well enough that there's room for everything within it. The space that we are using was formerly a patient room behind the nurses station in ward 2A. It was horrible for whoever was staying in it. It was not nurses' fault but they had to be able to communicate during the night and the lights had to be on for them to do their notes; it was never a great room for patients to stay in. Staff didn't like to put people in there unless they had to. It wasn't great for nurses either, access in cases of an emergency was restricted because their desk is directly in front of it. So the hospital has rejigged that space. I think the pharmacists have an office within some of that space too. The new ETYC room used to be a patient bedroom with the en-suite bathroom. It is quite central and the staff can keep an eye on the users of that room.
25. Surprisingly we've got a lot of money to spare after funding the ETYC room. We've helped buy a blood analyser for the Schiehallion ward. Within A&E and the Paediatric Intensive Care Unit ("PICU") at the RHC, the wards have their own blood analyser which means blood samples do not have to go through the central system within the hospital. If you are in a ward that has a blood analyser machine, within ten minutes maximum a patient can have a blood counts and any other important information from their blood sample. The difference that makes in this kind of environment is incredible; sometimes I could be waiting hours in Schiehallion and then I'd have to get my bloods redone because by the time it got through the system, it wasn't viable to be

tested anymore. It is a lengthy and unnecessary process, especially for the wee ones to get their bloods taken repeatedly. The blood analyser will make such a difference and will be used across wards 2A and 2B.

26. The last thing we hope to do with the funds raised is to create a resource within PICU; a relief for the staff. The difference between the Schiehallion ward 2A and with PICU is that whilst 2A is a high-dependency ward, the consultants can go home when they're on call. However all the staff within PICU, including the nurses, are in the patient's room from the start of their shift to the end of their shift, apart from their breaks. We would like to provide a space that staff can go to get a break, even get a nap if they could. We would like to ensure that the PICU staff are rested and at the top of their game. The PICU staff are incredible, and I think a well-deserved break would really make a difference. That's our grand plan at the moment and it is what we would like to pursue. We intend to speak to the same management that we've worked with for the ETYC room, to see if it is viable. If it isn't, then there are other things we can think about getting for the PICU to make people's lives easier.

## **SEQUENCE OF EVENTS: PATIENT EXPERIENCE AT THE RHC AND THE QEUH**

### **Diagnosis: January 2018**

27. I was not well for about six months before my diagnosis. Prior to that I never went to the doctor. Even if I had a cold, I was always still at school. During this time, I had cold sores or colds or flus that wouldn't go away. I had quite a large swelling on my side which was very painful. I struggled along and no pain relief was really touching it.
28. I had a big loss in appetite and lost a lot of weight. I was tired all the time. I attended school all week and I was working really hard as it was the lead up to National 5 exams. I was preparing to sit my prelims in January 2018 and was studying a lot. I'd come home from school and put my jammies on. Once

I'd done my homework, I'd have to go to my bed. At the weekend, I'd sleep. It wasn't really like me at all; I just wasn't right.

29. I went back and forward to different doctors for a while. I think it was to do with my age and the fact I was a girl, there were a number of things that they thought it might have been. Eventually I saw a GP that was a family friend of ours, and he knows me. Apart from the symptoms of the mass and the pain he noticed I had a cold sore that would not go away, and he suspected something was wrong. I saw him on Friday and I had a scan scheduled for the following week, on Tuesday 16 January 2018.
30. I had attended A&E at Inverclyde Royal Hospital ("IRH") a couple of times prior to that. A couple of weeks leading up to my diagnosis, the pain was getting really bad. There was one night that I couldn't sleep due to the pain and my mum woke my dad up and asked him if he'd take me up to A&E. He took me and blood was taken, but my bloods were fine then so I came back home.
31. On the 16 January 2018 I attended at my local hospital which is Inverclyde General Hospital for an ultrasound scan. I had quite a large mass on my side. Initially, they thought it was maybe my kidneys. I knew something was wrong right away, the staff performing the scan rang the consultant. I had gone for the scan on my own and my mum was in the waiting room. We weren't expecting anything like this to happen. The consultants came to speak to me and I was checked into A&E at IRH, and referred for a CT scan straightaway. The CT scan was performed and we waited for the consultant's report on it. One of the doctors who was working in A&E had actually worked in Schiehallion Unit in the RHC, and she came in and she told us that I had a sarcoma. She said that I had to go up to Schiehallion ward at the RHC right away and that the staff in Schiehallion knew I was coming.
32. We phoned my dad who was at work. He met us right away and drove us up to Glasgow. My brother was in his year abroad in [REDACTED], so he wasn't there at the time.

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33. When we arrived at the RHC I attended Ward 2B which is the day-care ward in the Schiehallion Unit. I met Dr Sastry. He did a few checks, he asked me about the type of pain I was having. Staff took a lot of blood samples from me and that night I was admitted to ward 2A RHC as an in-patient.
34. I was in ward 2B for a few hours while the staff made sure that I had a room to go to in ward 2A. They made sure I had a room that was at the very end of the ward. They ensured that I wasn't around many other people, had some privacy and I could be by myself. The staff were really good about that. Even when I was in initially in ward 2B, they made sure that I didn't have to sit in the middle of the ward and see everyone around me.
35. I was diagnosed with metastatic Ewing's sarcoma, with my primary site on my 11th rib. It was spread across the ribs above and below and in my diaphragm. I also had tumours in my lungs and in my tenth vertebrae.
36. That was my first day in Schiehallion. From the get-go, the staff were very soft in their language. It was never "you have cancer". Rather the language used was "there's this small mass, it's also here", "this is what we're going to do about it, we're going to treat it". I was never alarmed. I understood that something was wrong and I knew it was not good but it was never alarming in that sense. There was never this big horrible speech. I don't know if it is different for adults, but certainly within the children's unit the staff were really kind about how they communicated with me.

### **Ward 2B – the Schiehallion Unit: RHC**

37. Ward 2B is the Schiehallion day-care unit in the RHC. It's where child cancer patients go for day case appointments: blood samples, tests and check-ups. Some patients can receive their chemo there if they don't have to stay overnight and don't have to be admitted as an in-patient. It is a ward where
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staff can provide treatment without actually having to bring you in as an in-patient.

38. Day-care is also your first point of call when you're not well. Usually in non-COVID times, that's the first place you phone and that you attend when you have a temperature or if you just don't feel right. Patients might go to day-care if their bloods are low and they need a blood transfusion. A transfusion does not have to be an overnight procedure, a patient can attend in the morning, receive a transfusion that day and then go home that night.
39. The Schiehallion Unit is made up of Wards 2A for in-patients and ward 2B for out-patients. The ward staff work closely together. The doctors work across both wards, so as a patient you see the same doctors. There are some doctors that work in the day-care ward, and they work in 2A at the weekends for example. The position is slightly different with nursing staff. There are specific day-care nurses but that is because their shifts are different; they do not work 12-hour shifts, and therefore they can do more days. During the week, you always have the same nurses, and they take turns for who gets the day off that week depending on when their shift patterns. It tends to stay the same and you very easily build up a relationship with the staff there.
40. In ward 2B there was the waiting room and they had toys set out for the younger kids. Noreen, was the staff member who worked on the reception desk; everyone got on well with Noreen. She organised a lot of the things for patients, blood samples and appointments. The ward also had individual rooms where patients could see the doctors or where they might be placed if acutely unwell. When I first arrived in ward 2B, I went to one of the individual rooms and it was where I received my diagnosis.
41. There are treatment bays in day-care. There is a Teenage Cancer Trust four-bed bay and it is set up with chairs, but there is space for beds if needed. There is another bay for patients that are not teenagers, I think it has more than four seats, maybe six or eight, although I have never actually used the other bay. The bays might be used to receive chemo or blood products.

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## **Admission to Ward 2A – the Schiehallion Unit, RHC**

42. On the 16 January 2018 I was admitted as in-patient to room 7 in ward 2A in the Schiehallion Unit. I stayed for four nights and three days and was discharged on Saturday 20 January 2018.
43. Room 7 was not in the TCT but it was up at the end of the unit beside the TCT. There are four rooms in the TCT and at that time they were all occupied. I was still next to all the teenagers though.
44. Whilst I was not in a TCT room during the first admission, the staff still made sure there was an adult bed. The TV was a bit temperamental. It was just for couple of days so I wasn't too bothered. At the time I was shocked about my diagnosis. I was about to start my prelims a couple of days later. The only thing I could really think about was the fact that I'd studied for so long, and I wasn't going to be able to sit them. I was worried that I didn't get the chance and I spent a lot of time trying to organise school and my studies.
45. I didn't get back into school that academic year. Instead I sat my prelims at the same time as my exams. I took one day at a time, and sat my prelim the day before I sat the actual Nat 5 exams. I sat my prelims and my final exams in the first couple of weeks of May 2018.
46. The RHC had been sent my CT and ultrasound scans from IRH. The following day all the main scans went ahead in the RHC. I had two full MRIs, a biopsy and bilateral bone marrow aspirations. They did every test they could in order to find out how much the cancer had spread. Tests confirmed that the cancer wasn't in my bone marrow. I was informed that the tumour was malignant, and present in my initial site on my ribs, my lungs, and then my spine.

## **Hickman line**

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47. During that week I had a Hickman line fitted. It is a surgical procedure under general anaesthetic and was fitted the same day I had my bilateral bone marrow aspiration. I went down to theatre on the Friday and stayed overnight following the procedure just to make sure my line was okay, and then was discharged on Saturday 20 January 2018.
48. I had the Hickman line fitted and it is a bit different from a central line. A central line goes in your neck and down into the main vein into your heart, whereas a Hickman line goes in just at your armpit and it goes under the skin and in through the same place in your neck and down into the main vein into your heart. As the line goes into that main vein you have to be under general to get it fitted and to have it removed. A Hickman line is what all the kids tend to get, and it is more permanent.
49. A Hickman line is used for taking blood samples and receiving blood transfusions, and for administering medication. Due to the nature of the treatment, our veins are rubbish and collapse as soon as we start it. The line makes it easier than just using cannulas, it means we don't have to be jabbed so often.
50. The Hickman line has a dressing to cover it using something called a "seatbelt", it sticks on your body and your line fits in that. I got quite good at disguising my line in my clothes so that people were never really able to see it.
51. When you have a line, it has to be flushed every few days. When I was an out-patient I relied on the outreach nurses for that kind of thing, particularly if I was not attending day-care for a few days. When it was first fitted, I was newer to my line and was attending day-care more frequently.
52. Later on in my treatment, when I was not at day care as frequently, line flushes were sometimes carried out by an outreach nurse. That could even happen when I was at school. There are specific outreach nurses that work for Schiehallion. They cover different geographical areas so each patient had

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their own outreach nurse. I think there were three outreach nurses and they travelled all over Scotland. They flush lines, take bloods and sometimes if I was not well, they might check me too. They also attended my school and made sure that the staff were fully informed about what to do about my line in case there was an accident, for example if it was pulled and also to ensure they were informed about infection. They make sure you've got everything under control in that sense, that you're safe in whatever environment you are in.

53. A line flush is where a fluid is passed through your line to clear it, to ensure that the line didn't get blocked when it is not in use. The line is a tube into your heart so blood can flow back into it, but is locked off so nothing can come out the end. Blood is very sticky and it does stay in the line, so if it is not flushed it gets blocked and then you'd have to get a new line and that would be another operation. It is an important process.

### **Medical team and treatment plan**

54. Dr Sastry was my consultant. He is a paediatric oncologist. I had a very good relationship with Dr Sastry and have a lot of trust in him. If someone told me he walked on water, I'd believe it. He's incredible. It was Dr Sastry that spoke to me about my diagnosis and it was him that I dealt with primarily. I got on well with the majority of the staff and had good relationships with them. Patients call the younger doctors by their first names. There was Courtney, Ann-Marie, Suzanne and Albert. There were also FY1s and FY2s called Rebecca and James. All the doctors in the ward were incredible. You would be very hard pushed to find someone who chose to work in there that didn't have a big heart. It would be a hard job to do if you didn't.
55. Dr Sastry devised a treatment plan at that point and I was allowed out on the Saturday. The plan was that I would attend day-care the following week before starting chemotherapy the following Friday.

56. I was a bit older and got on well with the doctors. I'm sure they were great with the younger kids too. They knew what that I wanted to study medicine and all of them, Dr Sastry included, would explain everything to me in more detail than they had to; they knew that I wanted to know. The surgeons did the same thing, Mr Andrews, my main thoracic surgeon, talked me through the whole surgery.
57. As regards communication with me about matters related to my treatment, everything from the clinical staff was upfront. The language was very soft at the start. Dr Albert in particular was very good at knowing how my mind worked; he understood me and accepted that I wanted to know everything and communicated with me in a way that was good for me. A lot of people do not want to know everything and prefer to know only what they need to, and let the medical staff do what they have to do. It was a comfort to me to know and understand what was going on, and that made it a bit less scary.
58. All the clinical staff were always incredible at keeping me informed about my treatment. When they didn't know things, they'd say that and it was a comfort to me. The junior doctors were particularly good at that. I didn't like it when people used flowery answers in order to cover up what they didn't know. I liked it if someone was direct enough to say, "Look, I don't know but I'll find out". I knew where I was and I could never complain about that. For the most part, everyone was brilliant in that way. Even when things went wrong and when I caught infections, Dr Sastry, always told me, even when hospital management maybe didn't want him to be so upfront with me. He was very good at exercising his duty of candour and he was always told me what was wrong, why it was wrong, and what he was going to do to fix it. I speak about that in more detail later on.
59. I had a great trust in Dr Sastry. I like plans. I like things that are quite strict, but for cancer treatment plans there is wiggle room involved. He explained to me that my chemotherapy treatment was dependent on my blood counts, which meant that it wouldn't necessarily be an exact 21 day cycle for each block. My plan was organised and the staff knew exactly what they were

going to do; what each thing was going to target; how it was going to get rid of it. It gave me comfort. I liked knowing where it was going and why I was doing it. Ultimately the plan was like a checklist that I went through myself, each step closer to the end. For a lot of my friends on the ward, their parents dealt with this but I wanted to be involved.

60. The timescales in my plan were not exact. Nothing was exact with dates for surgeries and it was dependent on my blood counts coming back up in time for the 21 days to start. I could roughly work out when my treatment would finish give or take a month. I hoped to have surgery in the summer of 2018.

### **Description of Ward 2A – the Schiehallion Unit, RHC**

61. I spent the majority of my time in Ward 2A. There were four specific rooms that the Teenage Cancer Trust had completely funded. They are generally for ages 13 years and upwards, sometimes from 12 and a half years. The TCT rooms had adult-sized beds, they were bigger and the mattresses were better - but that was our secret! The rooms were created for bigger people. There was a parent's bed as well, it fitted into the wardrobe and it could be pulled down. My mum stayed overnight with me and my dad visited every day.
62. The rooms had wardrobes and cabinets. The TCT rooms had bigger wardrobes than the other rooms on the ward. You could hoard more things and it is possible to accumulate a lots of stuff while you're in there. There were drawers, one of the drawers was for all our own medicines; that's where I used to hide all my sweets too. We had space on the wall and there was a whiteboard so you could put stuff up. I tried to make my room my own. I had my duvet and other things brought in. The TCT bedrooms had bigger TVs too. They were all bigger than they are in other parts of the children's hospital and also the adult hospital.
63. The decoration and colours used in the TCT bedrooms were different. In the other rooms in ward 2A the rooms had rainbows on the wall, which is absolutely lovely for younger children but when you're a teenager and you're

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there for months at a time you don't really want to be staring at this rainbow the whole time. The TCT had worked hard to talk to teenagers about what they wanted and used colours that were calming. They put a lot of thought into it and it was a more grown-up environment.

64. We all had our own bathrooms in ward 2A. They were wet-rooms with showers and a toilet. It was a big bathroom so no matter your mobility, it was easy to manoeuvre. It was possible get a wheelchair in the bathroom. Sometimes if you were put on bed rest even if you were going from your bed to the bathroom, you still had to go in a wheelchair. There were railings fitted to the walls and emergency buzzers just in case. We all had our own space and we didn't have to share a bathroom.
65. Teenagers also had a TCT common room. It had TVs, a PlayStation, an X-box or whatever you wanted to play. We could sit on big sofas and there was a pool table. The common room also had a kitchen where we had our own fridge. My favourite thing was the table. It makes me sound quite sad that my favourite thing was the table, but I loved it. That's where I spent time with all my friends and that's where I did my schoolwork. It was really important that we were able to have that space.
66. Further down ward 2A, they tended to group patients together by age. The nurses station was halfway down the ward, and across from that was the playroom for the youngest kids. There was a parents' kitchen. We didn't really need to use that because we had TCT but that was where the majority of the patients would store any food they had. There were microwaves with a grill so you could reheat things, store anything you might need, and make a cup of tea.
67. Further down the ward there were transplant rooms. They had double-doors, and an area where people could gown up or take off their shoes, their jacket, everything, before entering the room, so it was all very safe. If a patient needed to isolate or if they were getting their transplant, there were rooms to accommodate that on ward 2A - unlike how it is now, where transplants are



split up on two different wards cross two different floors in wards 6A and 4B in the QEUH. Everything was done on ward 2A. It was our specific space; a wee safe haven.

68. Ward 2A was different to the other wards in the hospital. We had to live there and so those kinds of facilities, there was a lot of extra care put into them that might not be done in other wards. A lot of families funded and fundraised for the facilities and services when their children were better. For example there were snacks provided by fundraisers. People tried their hardest to make it a home from home, as much as it could be. It was never clinical.
69. Ronan was our TCT support coordinator. He was brilliant, everyone's pal. He worked for TCT and ensured that we had everything we needed, even if he was just coming and spending time with us. Thanks to Ronan I've got some of my closest friends. He was very good at knowing who you would get on with if you weren't sick; that was something that was really important. As much as you did have an understanding with people because you were all sick, it's life, not everyone's going to like each other. He was very good at knowing and understanding us, identifying who you would get on well with and introducing you to them. Ronan organised days out and group chats. It made it a lot easier having friends on the ward; someone to spend your time with. It made the days pass a lot quicker and that was the really hard thing about us moving from 2A into the QEUH. We went from being able to spend all day every day together and being able to make our own meals and sit and watch the TV, to being stuck in our rooms. Maybe if we went on a wee walk around the ward, you might pop in and see someone in their room but you didn't really spend time with anyone. It was isolating and being in hospital is isolating anyway.
70. Within the TCT common room, when people's counts were up high enough Ronan would order Domino's pizza for us. It very rare that everyone had counts high enough to allow us to do that so when it did happen it was a celebration. Otherwise Ronan went to the Marks and Spencer's, he knew what we liked and our eating habits and he would bring food up for us to eat.

We had days where we could just eat rubbish. During treatment we were

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encouraged to eat and anything was good. If it that was ice-cream, it was ice-cream.

71. We had a bit of a laugh on ward 2A. It was a very happy place, which a lot of people think is quite a weird thing to say, considering it is a cancer ward. The smaller kids didn't know what was going on, so they just played all day, running about in the trolleys and having races, standing on their trolleys. I worried that they would pull their lines out from all the running about! It was really happy and to go from somewhere which was a "home from home" to being confined to your hospital room was a bit of a shock. I know that not everyone is lucky enough to go to hospital and when they are there they have got somewhere comfortable to stay, where they watch TV and to sit and make friends. That was not the reason why were in hospital; we were there for treatment. Child patients and families were spending months and months at a time on the ward, so it was important that we had facilities that made it easier.
72. There were a number of charities that provided support on ward 2A. Different families had set up charities, a lot of these were in kids' names. For example, there was Team Jak who provided a snack trolley for the ward. There were crisps, sweets and juices. The charity staff figured out what you liked and for me it was the salt and vinegar crisps. People were so generous. The idea of kids with cancer broke a lot of people's hearts. For example, at Easter there was chocolate and so many Easter eggs. It was really nice. Everyone made a big effort to make life on the ward as easy as it could be, whether they were sending in toys or games or food.

### **Treatment: January 2018 to January 2019**

#### **Initial Chemotherapy treatment: January 2018 to May 2018**

73. In January 2018 I began treatment. My first six cycles involved a treatment called VIDE. It was four chemotherapy drugs that would alternate at the same time as having fluids. Initially I attended ward 2B where I was started on fluids and then I was transferred into 2A. I was admitted as an in-patient to ward 2A

and was hooked up for four whole days straight to IV medication. It was usually across five days, and I received all my chemo and my fluids and the other drugs to help with all the side-effects. The day I started, I only took some of my anti-sickness. I don't know why, for some reason I assumed that I could manage it. That was something I quickly changed for my next round of chemo. I made sure I took all the anti-sickness I could take. I underestimated chemo. I don't know what I was expecting but it was difficult. A lot of people I spoke to, they weren't necessarily hooked up for days the way I was, 24 hours a day. I was hooked up for quite an intense period.

74. It was a difficult time. Due to the nature of my diagnosis, there were a number of big decisions I had to make before I started my therapy. Right away I had to decide what would happen if I wanted to have kids. The chemotherapy that I needed and that I received meant that the likelihood of having kids after treatment is practically nothing. Therefore if I wanted kids of my own, there was the option get an operation in the hospital in Edinburgh to take a section of one of my ovaries. The whole procedure would have taken a period of three weeks and it had to happen before I started chemotherapy. I spoke to Dr Sastry. He didn't think that I had the time, and "waste" is the wrong word. It appeared that I might not be able to spend three weeks having that procedure, and I needed my treatment more. At the age of 15 years old I had to make that decision and I did make that decision. As much as I would have liked to, I didn't have the procedure and began treatment straight away. It is better I'm here. I can always adopt, but that was a hard pill to swallow.

75. I began chemotherapy and due to the intensity of my regime, I lost my hair really quickly all on one day. It happened after my first chemo which was unusual, it usually takes a couple of cycles. I went straight to the hairdresser. Girls are lucky in the sense that we can put on a wig, boys have a bit more difficulty. Whilst chemo was very physically demanding, emotionally there was a lot more to contend with to start with, which meant that the facilities on the ward were all the more important; to have people that understood, who you could talk to and spend time with people to take your mind off what was going

on. Just being able to access the TCT facilities for that support was incredible. It was amazing the positive difference it made to me.

76. I had my first round then I was discharged and I went home. I practically crawled to the car that first weekend and I really wasn't well after that. I didn't take all the anti-sickness I should have, which was a bit silly, I was being stoic. I then had to deal with the flushing of the line in between and things after I got out. Anne was my outreach nurse so she went with my dad to the school after that first chemo to talk about the procedure, for example, what would happen with my line. It goes into my heart, so if that was ever knocked out it would be very dangerous. I'd bleed out. Someone in school had to know what to do while they were waiting on an ambulance coming. Anne spoke to the school and her and my dad organised what would happen about prelims and schoolwork. It was really important to me that that all continued. That was my focus and I was adamant that I was going to be a doctor. It didn't scare me off it, quite the opposite as I was all the more determined.
77. For me day ten was the low point for my blood counts in the 21-day cycle, that was when I hit zero and had no immunity. A couple of days after my tenth day, I had my first temperature spike. That was normal and it was anticipated. I knew that my body might take a temperature spike as a reaction to the treatment.
78. For paediatrics a temperature spike is 38 degrees or above. If we are hovering at, say, 37.8, 37.7, 37.9 degrees, the staff tend to ask us to come in to the hospital. Sometimes we know before our temperature does. The nurses especially told us if we didn't feel right to come in because we know our own bodies.
79. When you spike a temperature the protocol is that you call the ward. The nurses tell you to take paracetamol and then you head up to the hospital. If you are more than an hour away you get an ambulance. The staff tell you to take paracetamol as they had to know and record the time it was taken. No matter what was wrong, even if your temperature was because of a cold, we

had to follow this procedure because it could change so quickly with us. That is why it was such a strict protocol and why our temperatures had to be checked every four hours whilst we were in hospital.

80. When I got to hospital I attended ward 2B where staff carried out a check-up: listened to my chest, took my blood pressure, took my temperature. From there I was admitted to 2A and IV antibiotics are given and blood cultures were taken. At that point the timer starts from the last spike, if you spike again then your 48 hours restarts. More often than not the cultures come back clear, but it's important that they know what's going on there. In order to be discharged, your temperature has to be below 38 degrees for 48 hours and provided the blood cultures don't show anything then you are allowed to go home.
81. When I had a temperature spike and this protocol commenced, the impact on my chemo treatment was dependent on where I was in my cycle. I always spiked on the tenth day of my cycle after I had my IV medication. I was allowed to restart the next cycle after the 21 days of the current cycle had finished, as long as my white blood counts had risen enough to start. If the counts were not high enough then treatment would be postponed until they rose.
82. My second chemotherapy was the first time I experienced mucositis. All the way from the mouth right through to the stomach is all one type of lining in your body. Chemo is incredible at killing off cancer cells, but it doesn't know the difference between the good and the bad cells, which is why you lose your hair. It also attacks these types of cells in the lining of the body, because they're really fast-replacing like hair, and the body just breaks down. It begins with ulcers and the lining peels away right through. The first time I had mucositis the nurses described it like it was third degree burns inside the body. It is painful. A lot of the kids experience it as a reaction to the treatment and in that sense it is quite a normal thing.

**Admission to wards 3A and 1E in the RHC: second cycle of chemotherapy**

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83. Just after day ten of this cycle, I had a temperature spike with pain and was admitted to ward 3A in the RHC. I started antibiotics and had both morphine and ketamine PCA for the pain. That was the first time that I experienced shifting between wards and it was awful. When I was admitted, because I was not requiring to receive chemotherapy treatment I didn't necessarily have to be on Schiehallion. Ward 2A didn't have enough beds, so I was admitted to 3A which is a more general ward.
84. It is Schiehallion protocol that we have our blood oxygen, our heart rate and our blood pressure and our temperature check every four hours without fail, and so that has to be done wherever we are. Unfortunately we often find that when we move to another ward, it's very difficult to keep up with that. There are different priorities on different wards. But that was the first time I experienced having to advocate for myself, of ensuring that the monitoring had to continue. I ended up getting these things called Tempadots that were very accurate for measuring temperatures. We used them at home and it's what staff used to take our temperature on Schiehallion. We got some Tempadots from Schiehallion so I could take my own temperature because the temperature thermometer that they were using on ward 3A was out and so my temperature was actually two degrees higher than was being read. Things like that that were difficult when not in Schiehallion. We are needy patients, there is no beating around the bush, and whenever we have to go elsewhere in the hospital issues can arise.
85. The only other wards that were consistent with the application of the Schiehallion protocol for monitoring were PICU and 1E in RHC which is cardiology; both wards have the same monitoring system as Schiehallion.
86. The Schiehallion doctors came to see us on their rounds after they'd finished the round on Schiehallion; they called us the boarders. Wherever we were staying they carried out a check-up and made sure we were all right during their morning rounds. Nursing-wise, you had the nurses from whatever ward you were on.

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87. It's no secret that the Schiehallion ward is referred to as the Hilton by other wards and that's often a barrier we come up against in wards that aren't as intense as Schiehallion, and 3A is one of them. During that admission I got to the point when I had to be given ketamine patient-controlled analgesia ("PCA"). I was moved to the Schiehallion because they can do ketamine PCA and teenagers don't really get morphine. We can but we're not supposed to get a high dose, it just makes teenagers sick, so I was thankful I was able to be moved.
88. After a few days, I was moved to ward 1E in the RHC because they needed the bed in 3A. I was better and I asked to go home after that, because I'd had enough of shifting about. That brought me to the end of that cycle and that was the first time I went past the 21 days. I had to wait for my blood counts to recover before I could begin the third cycle. At the time I was worried because I was concerned that this wasn't following my plan. Dr Sastry was very clear, he said he expected this to happen a couple of times and it was all okay.
89. Eventually I started my third cycle and it was a similar experience again. I started having mucositis very early in this cycle on the last day of my chemo. I went home but was back and forward to day-care for treatment. During the third cycle I started harvesting my stem cells and was put on injections that would stimulate my bone marrow to work harder. I harvested my stem cells in day-care during the break in my 21 day cycle. During that cycle I didn't spike and it was probably because of the bone marrow injections as my immune system had a bit more help. I got a bit of a break and that was the first time I went back to school for a whole day, this was in March 2018.
90. I started my fourth cycle and that was when things started to go a bit wrong again. On the 13 April 2018 it was the tenth day after my the fourth cycle, I was really unwell and I attended day-care. I had really low bloods. My CRP (C-Reactive Protein) was incredibly high, it is a marker they look for in your blood to check for infection. I needed blood transfusions and platelets too. I had an allergic reaction and whenever I get a blood product I have to get anti-

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histamine cover in case of a reaction. I was admitted to ward 2A as an in-patient. I was acutely unwell and had sepsis for the first time. [REDACTED] was home from [REDACTED] and he visited me when I took ill.

91. In addition I was reacting to the chemotherapy drugs and the soles of my feet had started to lose the skin. My feet were very raw and my neuropathy had got really bad. Neuropathy is nerve loss, the vincristine drug that was part of my treatment attacks your bone. It is very good for treating bone cancers but it's also very good at cutting off your nerves in your extremities in particular. I began to experience trouble walking. I started using crutches at this point and the hospital performed x-rays and tests on my nerves. I got a wheelchair as I couldn't really walk: it was the best thing but that was a low point for me. I felt like I started to look sick. I could throw on a wig and I could do my makeup when I saw my friends and I would look perfectly healthy, but I hated being in a wheelchair. Things started to take a mental toll in April 2018.
92. Unfortunately I was due to start my prelims on the last day in April and it wasn't the best timing. I was an in-patient for a while and was discharged on 20 April 2018. I had issues with my blood count not coming up so my next round of chemotherapy had to be pushed back a week. I managed to sit my first exam at home on 30 April 2018. The next day on 1 May I started my fifth chemotherapy cycle and was admitted to 2A for four days of IV chemo. This time I sat my French prelim, my maths prelim and my maths final exam, all in the hospital while in receipt of the fifth cycle of chemotherapy.
93. I had a lot of anti-sickness drugs to get me through it but I did it. The exams helped to pass the time in that cycle. In hindsight, I have no idea how I did it though. This was not the plan: had I not experienced the push backs on my previous chemo cycles I would have been out of hospital to sit my exams. Due to the push backs and because I hadn't been well I had to sit my exams in the ward. This was the start of things getting bad and of the infection starting but I didn't know it at the time. Everyone on the ward made provision for me, the staff were so excited, they put up posters, like "exams in



progress", "everyone quiet". I was the first to sit exams on the ward, it was quite a big deal.

94. I was admitted to ward 2A with another temperature spike on 9 May 2018. Blood cultures were taken but nothing came back at that time. I was an in-patient for a week and was discharged on 16 May 2018. My temperature came down and like before it was hovering under 38 degrees, but I was allowed to go home and then start my next cycle. We knew something was coming, during that admission I kept spiking. A temperature spike is 38 degrees. I had really high temperatures and they never quite came down, they always came to 37.8 degrees and sat there. My temperature was hovering and it was not a good sign but I was allowed to go home.
95. I began my sixth cycle of chemo on the 22 May 2018 and was discharged on 26 May 2018. I really wasn't well on the tenth day after the sixth cycle. I was admitted to ward 2A on 31 May 2018. This was the second time that I was rigoring with the high temperature. My haemoglobin was on the floor. I needed a few blood transfusions. My rigors were going crazy and I was given boluses which is fluid resuscitation. That was the second time that had happened. This seemed to be worse this time.
96. It was really, quite frightening. There were eight or nine members of staff in the room all trying to get access via a vein. My line could not be used as it was believed to be the problem because my haemoglobin was so low and because my temperature was so high. My body was in septic shock, my extremities started to shut down to keep the blood where it needs to be in the main central system. It was hard for staff to get a line in my veins and that was why there were so many of them in the room.

#### **Healthcare associated infection: *Mycobacterium chelonae* – May/June 2018**

97. I found out about the mycobacterium on 1 June 2018. However the result was from blood cultures that they had taken from me on 9 May 2018 when I was admitted after my fifth cycle. It took until 31 May 2018 for the mycobacterium
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chelonae to grow. It is called the silent bacteria because it can take 20 days to grow. That is a lot longer than the usual 48 hour for blood cultures, unless you have the special bottles for mycobacterium, which the hospital didn't have because they didn't anticipate it was this bacteria. Therefore it took a long time to grow.

98. On 1 June 2018 Dr Sastry told me that I had a bug called mycobacterium chelonae. He told me that it was an environmental bug, most likely waterborne, and that I would have to have IV antibiotics for at that time they believed to be two months before I would continue on oral antibiotics and we would have to liaise with a specialist in Edinburgh because no one really knew and understood what this bug was. It wasn't normal.
99. He was very upfront that he didn't know anyone that had had it and he'd never dealt with it. He said he understood that it was the first case in 20-something years in paediatrics, that it was an environmental bacteria and it was usually water related. He was also upfront that they were just going to have to wait and see how to treat it and that he was going to have to trust the specialist, Professor Lawrence, who he was in discussion with in Edinburgh.
100. That was when I saw Dr Sastry waver a bit. That was when he was starting to be held accountable for that which he was not responsible. Dr Sastry was responsible for my whole treatment and my overall health, meaning antibiotics and other medications and procedures. However, I was made sicker by the environment, therefore he was being held responsible for something which should not have happened, he had to come up with treatment plans for things other than my cancer. He had to start balancing what was more important: was it treating me for this bug and not giving me my chemotherapy which in turn could cause cancer to take hold, or would it be giving me my chemotherapy, bringing my immune system down and making the bug take hold? It was scary enough without having to see the staff not knowing what to do. It is an impossible decision. It's something that no one should ever have to decide. It was a balancing act. It wasn't fair for Dr Sastry.

101. On 1 June 2018 I had an emergency surgery under general anaesthetic to remove my Hickman line. I was put on PCA for pain relief.
102. I started on IV antibiotics, all day every day. I was on them for a month. No one in the hospital had really used these antibiotics and I don't know what type they were. Half the time, the nurses couldn't even pronounce them. The side-effects that came with the antibiotics were horrible. It was like bleach running through my system so I was really very ill and I unfortunately started to have problems.
103. I kept collapsing. The staff found out that the electrical activity of my heart was off so when my heart pumped blood it wouldn't fill up quickly enough which would cause me to collapse. I was confined to my bed, I wasn't allowed out of my bed unless it was to use a commode. At the age of 16 years old this was embarrassing. It's just yet another bit of dignity that was taken away from me at that point. It was not fair.
104. Eventually I was allowed to get a line again, but before that I had to have cannulas all the time and the staff were really having a hard time with them. My cannulas kept tissueing which is when my veins would collapse and so the cannula would come out of my vein but it would still be in my hand so while the medicines were going in, it pumped into the surrounding tissue and that would solidify and swell up. It was painful. My veins just weren't having it. If I hadn't caught the bug then I wouldn't have had to go through this; on that view this was unnecessary but I needed my antibiotics.
105. Due to what had happened and the impact of the bug on my treatment plan, I couldn't have my surgery at that point. My treatment plan had to change. Instead of surgery I went straight onto the next chemotherapy block. This was yet another cause of anxiety because I don't like plans changing, I like organisation.
106. I was an in-patient for the whole of June 2018. Professor Lawrence in Edinburgh had said that he thought that the month would be enough at this

point, and so from doing the two months of IVs I just did one month then I went straight onto oral antibiotics, so I was allowed home. I still had to attend day-care in between then for a couple of days. I think I got about a week home and then I was back in again for chemo.

107. I didn't have a new line fitted straight away, the doctors wanted to get the bug under control first before they put more plastic in my body, because the line is plastic and the bug likes to cling to things like that. A new line meant another surgery and another general anaesthetic.

108. So my new line was fitted under general anaesthetic. Dr Sastry had to re-arrange my plan. I started a different regime of chemotherapy and the new plan was that I have my surgery after my tenth chemo. After surgery I'd have two chemotherapies to round up any last remaining cells after surgery.

109. The regime required three days IV treatment instead of four whole days, and it was a new drug and two were dropped. I underwent radiotherapy at the same time.

110. My dad and I went back and forward to the hospital every day. I had my weekends at home. I continued to experience issues still with my mobility and I still was in a wheelchair. Mentally I wasn't good because I didn't have my focus anymore. A lot of my friends had now left. They'd all finished treatment so it was just me and I had this bug and I had no idea if it was actually treated: no one could tell me that, no one could tell me if it was gone, if it was going to come back, what it was going to do. No one really had many answers.

111. That was when I became more aware of issues my dad was dealing with in the background, he was trying to find out what this bug was. The thing that always got me was that management never spoke to me and as much as I get that I was under 16 and they were dealing with my Dad, all of the doctors on the ward never saw my age as an issue. With the clinical staff, Mum and Dad would always be present, but the staff always spoke to me. This change in communication was new and that was uncomfortable. It was something that I

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had to start dealing with, which was that they were not always going to come straight to me when that bug came on board.

### **Surgery: 19 October 2018**

112. I continued to receive treatment. I was admitted in between treatment for mucositis after all the chemo. Eventually I finished my radiotherapy and I was generally okay. The bug seemed to be gone. I was still on antibiotics and my surgery was scheduled for 19 October 2018. Prior to surgery I was given two weeks of a break at home.

113. The night before surgery I was admitted to the surgical ward 3A in RHC. I knew that it was a big operation, the surgeon was operating on my chest and I was aware of all the complications that entailed. I knew they were working with my diaphragm, and that I might have difficulties breathing. I knew recovery was going to be painful. I knew I needed reconstruction surgery. The surgeons talked me through it all and I was generally okay with it. I had a lot of faith in my surgeons and the night before surgery I refused a sedative which is normal procedure for the kids that get the big surgeries; we usually get a sedative. I genuinely felt I didn't need it, but later at night I couldn't stop shaking and everyone thought it was maybe nerves. Eventually I thought, "Maybe I am nervous."

114. I was adamant that I was okay, but one thing the staff didn't do was the Schiehallion protocol of testing my temperature overnight every four hours. I was first on the list the following morning for surgery. On the morning of 19 October 2018, everything was signed and ready to go. I was in my gown, the bed was outside the room, and ready to take me down to theatre. I even had my surgical stockings on. The surgical team were performing the last checks, and they checked my temperature. It was over 40 degrees, which is incredibly high. The anaesthetist said she wasn't happy, it wasn't like it was just a couple of points of a degree over, it was a few degrees. She said it was way too high and she was not taking the risk. She was very apologetic. Of course I was grateful that no one was taking the risk.

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115. I was admitted to ward 6A. At this point Schiehallion had moved from the RHC to ward 6A in the QEUH. I started on IV antibiotics again. Staff took all the blood cultures. This time they had the proper blood culture bottles for mycobacterium and it was confirmed fairly quickly that it was mycobacterium. In the anaesthetist's words, "Thank God we didn't do the surgery because had it gone ahead with that bug on board, it would have been catastrophic". I understood that to mean that I probably wouldn't have woken up. I think someone was looking out for me that day, that's the only way to put it.

116. I had my line removed again, this being the second time my central line was removed. After a few weeks in order to resume chemotherapy, I was given a PICC line in my arm, I had a line going into and just up my arm so I could continue getting my antibiotics and my chemotherapy.

117. I started again on antibiotics for the bug, only this time the doctors had to think of new ones because the bug was likely resistant to the antibiotics that I had been on before. We sat down with Dr Christine Peters, the microbiologist who had been liaising with Professor Lawrence in Edinburgh, and Dr Sastry. They came up with a different group of antibiotics for me to start on; each as horrible as the last. And at that point I asked the doctors if they knew that it wasn't going to come back again. They were quite frank and said that they didn't know, that they could only try. This time I was prescribed two months' IV antibiotics and I started on that.

118. As horrible as it was the last time being hooked up all day and overnight to antibiotics, this time the issue was that I was in ward 6A. I didn't have the TCT. I didn't have any of my friends around me. I didn't have the opportunity to leave the room. I didn't have a kitchen. Depending on who was working, they'd make a hot water bottle for me, but the facilities were lacking. I felt very sick and was back to that mind-set of "Yes, you are sick". In 6A the TVs were always broken; if they were working, they were a lot smaller in the adult hospital. My mum didn't have a proper bed. My mum has rheumatoid arthritis and she had a bed she had to pull down every night and try and shift the

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mattress on top. I was concerned at mum having to do this when it was already hard enough her dealing with me.

119. At this point we were all acutely aware of all the issues going on in the hospital. We weren't in our ward and most days we would find out what was going on from the news before we would find out from any management staff. The clinical staff didn't know what was going on either, they were finding out what was happening on their way to work in the morning from the radio. There was no one telling us what was happening. Very rarely did anyone come round and say "This is what's happening, this is what we're doing to fix it". You could see how exasperated the clinical staff were, they knew something was wrong and they had all these other problems they had to balance with providing care: prophylaxis, the antibiotics. You could see the trust was breaking down between clinical staff and patients and you need trust during all that.

120. I still had complete trust in Dr Sastry. Staff told me that I was going to be okay with this bug, no one could say that it wasn't going to come back in another couple of months' time. Most of the time I thought "Why was I feeling so bad if it was going to come back?". It made it very difficult to focus on school. I had been doing six Highers but I had to drop three, so I only did English, Spanish and French. That impacted on what I wanted to do. To study medicine I needed five 'A's first time and I needed sciences. I couldn't do sciences because I was stuck in the hospital. I couldn't get in to school to do the assignment which was an experiment. I couldn't sit any sciences. I still applied for medicine at university, but I knew at that point that I wasn't getting in to the course. It was yet another thing to contend with; another thing that was taken away. It is difficult enough having cancer as a teenager never mind everything else that's thrown at you: the bugs and extra time in hospital, extra sickness, extra complications. I had an issue with my heart, the long QT and staff had to balance medications. They had to consider the benefit of stopping symptoms versus what it was going to do to my heart; it was yet another balancing act that they shouldn't have been required to undertake.

121. Prior to starting these antibiotics, I'd had my kidney tested. Every two chemo treatments I received a kidney function test. My kidney function had remained steady at 98 per cent the whole way through treatment and it was still at that point in October 2018. They tested it again in December 2018 and it had reduced to 54 per cent. No one could categorically say what caused the reduction in kidney function, but the only thing that was different in terms of my treatment was that I was on all of those new antibiotics; ones that were known to cause issues with your kidneys. At that point I knew that would cause issues for me, also taking into account the fact that I hadn't had my surgery and I had to go away with my other chemos to make sure that they finished. The change in my treatment plan meant that I wasn't going to be able to have two final chemos after my surgery to mop up any cells, to ensure cells weren't left over. I ended up having these chemos before surgery rather than after. I had to just trust in the surgeons to ensure there was nothing left behind and that's not something that they could definitely control.

122. If no one else in the ward had this bug, how do they know the treatment was going to work, and how do they know the bug was gone? Another worry that I thought about all the time was what this was doing for the cancer, which of course was the reason I was there in the first place. I knew that my particular diagnosis was difficult and I knew that the chances of it coming back were high, but it was unsettling to know that what would be the preferred treatment plan was no longer viable.

123. It was hard to feel completely safe at that point and it was nothing to do with the clinical staff because I trusted them implicitly. I knew that I had the best care and I could only put my trust in them, but I would have had to be blind not to see the issues in the building itself. It was very uneasy. I got out just before Christmas, everyone made it their mission to help me get out. I was discharged on 21 December 2018. I was still on oral antibiotics. My surgery was scheduled for 16 January 2019 which was a year to the day of my diagnosis.

**Surgery: 16 January 2019**

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124. I had my surgery on 16 January 2019. Following surgery I was admitted to ward 3A in the RHC. The drugs I was given differed depending on the ward I was in. For example, after my surgery, I wasn't supposed to be sick, because I'd just had surgery on my abdomen and chest wall. I wasn't supposed to be on morphine because teenagers got really sick on morphine. Originally it was intended that I would go into PICU but I went back to the surgical ward 3A instead. There wasn't a bed in PICU. As I was on surgical, they wouldn't give me ketamine, which is the PCA I would have been given if I was in Schiehallion. The epidural that I had been given didn't work because of the tumour in my spine, so I was without pain relief for three days until eventually the doctors from Schiehallion kicked up that much of a stink. On the first night a PICU nurse gave me a special PCA, so I could get ketamine, and then after that Schiehallion nurses came and gave me pain relief.

#### **February 2019 to August 2019**

125. Following surgery I finished treatment. My scans were clear and I rang the bell in February of 2019 to mark the end of my treatment. I still attended day-care because of the antibiotics I was on. Due to the side effects and other problems they were creating, I had a lot of problems in my gastro system. I had trouble absorbing anything from my food so I was on supplements to try and keep my vitamins and my electrolytes up. I had to constantly go for ECGs because of all the medications I was on, to make sure that that electrical activity in my heart was okay and it wasn't going to cause an arrhythmia. The antibiotics made me quite sick and due to the side-effects I was constantly being monitored and having my bloods checked up at the hospital.

126. My PICC line was removed just before I got home in February 2019, so I had to be jabbed constantly when I was up at the hospital. I think the nurses used to dread when someone had to take my bloods when I was going up to day-care.

127. I stopped taking the antibiotics for the mycobacterium chelonae in July 2019. This was agreed between Professor Lawrence and Dr Sastry because the antibiotics were doing me more harm than good. Initially they had expected me to be on them longer but because of all my gastro issues, they didn't think it was good that I continued taking them any longer.

### **Communication about another case of Mycobacterium Chelonea: July 2019**

128. I was back and forward between February 2019 and summer of 2019. On one occasion in July 2019 my dad was away on work, my mum and I were in day-care for a check-up as usual, so we didn't anticipate anything happening. Dr Sastry sat us down and told us that someone else had contracted mycobacterium chelonae.

129. I built up a relationship with a lot of kids on that ward. When I was in 6A everyone did their own walks around the unit and said hello. Eventually I got really close with a lot of the wee kids, but I also had other friends from TCT too. All I could think about was who it was and were they okay. The only reason I was ever okay when I had sepsis was because I lived under an hour away and got to the hospital in time. You only have an hour to get to hospital when you have sepsis. Maybe they weren't checking their temperature, maybe they didn't know?

130. It was in IMT minutes that my dad was to be told so Dr Sastry was under the impression we had been told at this point, but of course we hadn't been told. When Dr Sastry realised we didn't know, he told my mum and I himself as he felt it was right that we knew. After he told us, he was on the phone to a member of the management team about the fact that he had told us. He had to step out the room because we could hear the conversation on the phone. It all went very quiet when they found out that we knew. We later found out that an order was given that someone was to tell my dad but that message had never been passed on. This comes back to what I said about how I completely trust Dr Sastry, his communication was always amazing. He felt

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that it was part of his duty of care that he had to tell me. In terms of trying to investigate what happened, the only reason a lot of things weren't getting done was because it was thought that I was an isolated case. But this was no longer the case and it would benefit to know if anything was connected.

131. It was really hard for me knowing that someone else had mycobacterium chelonae. I was very close with a lot of the wee kids and the idea of them being that sick and them potentially having to go through that was really difficult to deal with. Of course I was never told who it was, that would be wrong, but amongst patients you end up finding out. We speak to each other and we end up telling each other; of course, the staff never told me who it was. I now know that the other patient is okay, and I'm so glad but at the time I didn't know that.

132. This event set me off again and this was when I started to get really angry. There seemed to be no answers. No one was really learning or listening. Certainly not anyone outwith the clinical staff, and we could see the frustration within our team on the ward. They wanted something to be done.

### **Relapse: August 2019**

133. It wasn't long after that that I relapsed. That was in August 2019. As my kidney function was reduced, my options were limited. There were a lot of things clinicians couldn't do because my kidneys would shut down. I presented with: maintenance chemotherapy to give me time; a lighter chemotherapy that might work but unlikely; or we could take the risk on my kidneys and try a programme called ME-ME which was really, intense chemotherapy followed by a stem cell transplant. For the intense option the chemotherapy would be so harsh that my counts wouldn't recover, therefore I'd need a stem cell transplant for my blood. Thankfully Dr Sastry had the foresight to harvest my stem cells in 2018, so I could be my own donor and there would be no rejection.

134. The risk was whether my kidneys would be able to take it or not, but for me that wasn't really a choice. Of course I was going to try, I'd never forgive myself if I didn't. I chose to go ahead with the intense chemo and the stem cell transplant. The plan was that I would undergo this treatment twice: chemo and transplant.
135. Before that I asked if I could go onto the maintenance chemo to get them all over with. To me, it was important to do something as important as that in case things didn't go okay. They let me do that and so I did. As it was on a form of chemotherapy, I had temperature spikes. I was back and forward to the hospital but I was never put back on antifungal prophylaxis because of my long QT in my heart. We didn't anticipate me having to be in the hospital building that much. It was expected that I wouldn't need antifungal prophylaxis because it would cause more harm than good at that point. Of course things are never that simple with me. I took temperatures which meant I had to go in as an in-patient a couple of times. I was in the hospital with no prophylaxis on board. In November 2019 I was admitted to the hospital with PCP pneumonia and I ended up in PICU because I needed help to breathe.

**Admission: November 2019 - pneumonia**

136. I was an in-patient for about a month. PCP pneumonia is fungal pneumonia. Dr Sastry believed that the most likely cause was because I wasn't on the antifungal prophylaxis. That is something I don't know for sure but it was yet another thing.
137. I got out of hospital just in time for my Make A Wish in the December 2019, just before Christmas. I had a respiratory physio and it was a big deal for her to get my lungs working again so that I was able to sing with Paolo Nutini. Everyone was helpful and made sure that I got out in time to do something good for me.
138. We were waiting on kidney results, and if they deteriorated any more, I wouldn't be able to get the stem cell transplant. Dr Sastry let me go on holiday

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with my family. I went away at the start of January 2020 to Dubai. The day I came back, I got a phone call to say that my kidney results hadn't dropped. The next day I went in to the hospital to get another line fitted so I could receive my stem cell transplant.

### **Stem cell transplant: January 2020**

139. When I had my transplant that I asked to receive the transplant in ward 4B, because I wasn't getting a donor for my stem cells there was an argument that I stay on 6A. However a couple of nurses on the ward had advised us to really argue for receipt of the transplant in ward 4B.

140. They said just to make sure I was in Ward 4B because the nursing is practically one to one and that is needed after transplant and the ventilation in the ward was different. I believe that ward 4B had its own ventilation system because it was a transplant ward. I think it was similar to what it was supposed to be on Schiehallion that we had our own system in ward 2A. I don't know exactly how the different systems worked. The nurses that were close to us advised me to ask to go to 4B for those reasons. We did argue the case and eventually I was transferred to ward 4B for transplant after I'd had finished my conditioning chemo. But I wasn't on 4B particularly long because I went to PICU where I stayed for 18 or 19 days and then I just went back up to 6A rather than returning to 4B.

141. I knew the transplant was going to be harsh. The melphalan in the drugs in particular, you're only supposed to get one dose but because of the sarcoma I got four days of it. The doctors were a bit worried and they kept coming in to check on me. However it wasn't the melphalan that was the problem. On the Sunday of my conditioning chemotherapy, I was given an overdose of etoposide phosphate, which was one of my chemotherapy drugs. I was given 14 per cent extra, and that all came with its problems. I got mucositis and according to the doctors, it was the worst they'd ever seen. The dentist couldn't believe it. I lost a whole part of my tongue. Everything had burned away and it that was the chemo that did that.

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142. I was admitted to PICU because of the pain relief that I required. Given the amounts of pain relief that I was on, it was very easy to forget how to breathe and I did that couple of times, giving everyone around me a fright.

143. On Tuesday night I was admitted to PICU and on the Wednesday morning I had an episode of delirium. It was due to the combination of drugs in my system and I was thinking about the overdose and the bug and all of the other things that seemed to go wrong. I had a manic episode where I thought that everyone was out to get me and I didn't really recognise anyone, including my mum. I tried to take my line out and I managed a bit but staff stopped me in time. I was given propofol and was knocked out for a bit. The emergency buzzers went off. All the staff were in the room and lots of staff came down from Schiehallion. Dr Sastry didn't come in the room just because of how I was, he wanted to maintain the same kind of relationship with him.

144. This happened due to of the amount of medication I was on because of the pain I was in. My pain didn't seem to go away and it seemed to be getting worse. There were different pain reviews and there was a change of pain medication to see if it would make a difference.

145. Eventually clinicians found out there was a problem with my liver. At the time they thought it was VOD, which is veno-occlusive disease, which is something that they anticipate can happen with my treatment, so I was treated for veno-occlusive disease. There is no treatment as such, they ensure that you have platelets because you go through platelets very fast when your liver's got problems. The staff were having to get the freshest platelets they could and pump them into me. Because of that and due to my blood type not being the most common, something happened with one of the bags. I don't know if it wasn't completely screened, but I was given a bag of platelets that had a bug in it, a bug responsible for acne. Acne is not a big deal to people, but I had just had my transplant so I had no immune system. A newborn baby had more of an immune system than me because they have their part of their mum's

defence antibodies. When you have a stem cell transplant you have absolutely nothing.

146. This new bug was on board, but at that time I didn't know it was there. I started having the temperatures again and similar symptoms to the mycobacterium chelonae bug. I thought it was back and that was something I feared because having the transplant could knock my immune system back, allowing the bug to rear its ugly head.

147. Dr Sastry wasn't there, he was away on a conference, so it wasn't him responsible for me that week and it was another doctor. He decided that they felt it would do more harm than good to tell me about the acne bug at that point. This is where my dad and my opinion differs. He thinks that that was the right thing, I don't. I would have preferred to have known rather than think the bug was on board. I understand why they did what they did and why they didn't tell me. They wanted to wait until I was a bit more stable before they told me something like that, especially after what happened with the delirium.

148. I understand it. Maybe it is just me being stubborn, wanting to know. But it was yet another thing; every time I'd tell this story I just seemed to have problem after problem but that's just the way it's gone for me. I seemed to get every side-effect, every problem. In terms of future options, I can't go ahead with the second stem cell transplant because of the issues with my liver. Surprisingly my kidneys stood up and they've not changed, but my liver is really damaged. Now clinicians don't think it was veno-occlusive disease. It looks like I have chronic liver disease and that will never go away, whereas veno-occlusive disease does.

### **June 2021**

149. I managed to get a year post-transplant then unfortunately a tumour they had believed to have been dead has grown in the last couple of months; so it's back. I will start radiotherapy in a couple of weeks, a new type of radiotherapy that's subablative. Where I'm sitting now, there are limited options for treatment.

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I've got my problems with neuropathy, so I still can't feel my feet or my fingertips properly. I can walk better, but it is not great. I've got chronic liver disease. I have half of the kidney function I should have. I've lost the highest pitches of my hearing because of the antibiotics. I've got prolonged QT in my heart. As regards my gastro system, I have problems with absorption. I have oesophageal motility and I can't swallow food properly. I can't get the right nutrients from food, there are certain things I cannot eat and my diet had to completely change.

### **PHYSICAL EFFECTS**

150. I'm still here, but there's a lot of things wrong with me that shouldn't be. I shouldn't have lost parts of my hearing, nor should I have reduced kidney function or have my liver not working. Neuropathy, is expected from the cancer treatment. I probably shouldn't have the prolonged QT but I was on too many drugs that that was inevitable. These are all avoidable things that I now have to live with. In the event that cancer comes back, these physical effects make my options for future treatment very reduced. Thankfully, at the moment I have just one isolated tumour which is treatable, but if it wasn't then I would be in a very different position right now.

151. In terms of my treatment options, there's not very much we can do because of all of the physical issues I have. My body probably wouldn't be able to take it. It is a worrying situation.

152. I also have to contend with the fact that the mycobacterium chelonae bug could come back at any time. It's a cousin of tuberculosis and it lies dormant in the body. I will never be rid of it. I can only hope that it is suppressed enough. As long as I don't need any more treatment, I hope that it stays that way. If I ever I need any more chemotherapy treatment, it should stay suppressed but I can't guarantee that.

### **EMOTIONAL EFFECTS**

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153. As regards the emotional effects related to the building and what happened, when I was first diagnosed, I didn't get upset as such. Obviously I was upset but I didn't need help. I didn't need to speak to anyone as I'm quite good at dealing with things. But there's only so much someone can take and with everything that went wrong, everything that could have been prevented, I ended up at the stage that I couldn't deal with it myself and was in quite a low, dark place. I needed my psychologist for help, and it is something I don't like to think that I need. It's not something I ever wanted. I would have dealt with it myself if I could have, but it's now at the stage I can't and so every two weeks, if not every week, I have a space available every week to speak to my psychologist. We go back and forward and I don't know really where I'd be if I didn't have that.

#### **IMPACT OF THE MOVE OF SCHIEHALLION TO WARD 6A IN THE QUEH**

154. After the move to Ward 6A, Ronan's job got very difficult. All he was able to do was go around the rooms, see people individually and spend time with us individually. He tried once or twice to get us organised into this wee corner room, but invariably the doctors needed it because they didn't even have enough facilities on ward 6A either. Any kind of socialising was dropped. I tended to get pizzas more often because that was the only good thing, because if you weren't with other people, if your counts were good, you would get pizza.

155. We all became very isolated. Ronan had to split his time and run about the ward to see people so that they weren't on their own. He would get things just to keep people occupied and try and organise games. There was only one mobile PlayStation so unless you had your own, you probably didn't get to use it as much. It was easier to be sick then; for a lot of us "sick" was a mindset too. It was easier to believe you were sick when you were in ward 6A. The food in hospital is horrible and there's no sugar-coating it. No one ate it, and we really heavily relied on the TCT kitchen and the parents' kitchen in ward 2A. Once they were gone, that was it. We were either forced to eat what was

on the trolley or you didn't eat and you had a feeding tube. The first time I got a feeding tube was on 6A.

156. After ward 2A closed, it was difficult for the charities to access ward 6A. Ward 6A was quite full as both wards 2A and 2B were moved to ward 6A. Day-care patients were coming and going. It was hard for charities to come in, but they handed sweets in and they were brought round our rooms. Eventually a parents' kitchen was created, but it wasn't the same. It didn't have the same space or fridge or facilities; but it was something. That was done latterly when I was in at Christmas. The only Christmas I had in hospital was in 6A. I am told by other patients and staff that it was different. For example we used to have different football teams come in to see the kids, and that Christmas they still came round but they would see people individually, whereas before I know a lot of my friends all met footballers and rugby teams together.

157. One of my closest friends on the ward was a big Rangers fan and I would have absolutely loved to see his face when the Celtic team came in. It became more difficult to facilitate things. It wasn't the same atmosphere on ward 6A. People were striving to make things easier for patients, but it was harder for them to do that. The move made a lot of people's lives very, very difficult.

158. There should have been a lot of activities organised that couldn't take place because we were all in separate rooms. There was nowhere to meet. We were still very lucky though. People sent gifts and food. We still got all of that but individually. The isolation was difficult. Group activities couldn't happen.

### **PREVENTATIVE MEDICATION**

159. I was on prophylactic medication. From the very start of chemo, depending on age, patients are put on cotrimoxazole which is a broad spectrum antibiotic. As I was a teenager I got it more often. I was always on antifungals as well, one was fluconazole I think.

160. At the start of treatment we just believed that was normal and it might have been. As 2018 progressed and when everything started to go wrong for me and in the hospital, we were aware that all the other patients were on these medications, particularly the antifungals, and that it was due to the issues with the hospital.

161. We were told that it was because of the issue with the cladding at the entrance to the front of the RHC, that everyone was on antifungals. Dr Sastry was always quite frank with me. I'm not entirely sure how I found out, because a lot of the time we knew things because of my dad pursuing things and other times we knew because of Dr Sastry, so there was a bit of overlap there. Certainly with the antifungals, Dr Sastry was very upfront with me, because he was quite frank when I got the PCP pneumonia that I had to be on antifungals.

## **WATER**

162. When I was first admitted to ward 2A in January 2018, I was able to use the water. There were signs up in the rooms saying that we had to run the water for three minutes before going in the shower. We weren't on bottled water at that point. We were allowed to fill up the kettle from the tap, but then in February 2018 we weren't allowed to do that anymore. At that point we started to use bottled water and then that was when things started to change, occasionally the water was switched off in the wards and we were not allowed to use the toilet, we had to use bedpans. For patients bedpans are fine if you have to be monitored, but if you weren't on fluids and you didn't need to be monitored, it was horrible. The staff brought these stands into the wards for washing hands, like what you would get to wash your hands at a festival. It was horrible.

163. There were filters on all the taps and on the showerheads. People would come into the patient rooms and test the water with these filters on quite regularly. I got used to guys coming into my room fairly regularly on both wards 2A and on 6A.

164. The filters were put on after the issues with the water started coming about in around 2018. We were just told via written letters from management and general discussion on the ward that the filters were to filter out whatever was in the water. We didn't know what it was in the water, we just knew there was something that wasn't good so they had to put filters on to make sure that it didn't affect us.

165. We just kind of knew there was an issue with water, we didn't know what was wrong. It was all very disjointed. No one exactly knew what was going on. The staff didn't exactly know what was going on. We were just told not to use it. We used to get letters and they would send it round the lead nurse on the ward to come round and she told us that for the next however many hours we couldn't use the water.

166. Bottled water was introduced in February 2018 and we have been drinking that on the wards ever since, in both wards 2A and 6A. The water was okay to shower in apart from one time when the water was turned off. When the patients were moved from ward 2A to ward 6A we were told it was a different water supply. Once we were in 6A, the management came round with the lead nurse and they were very quick to reassure us that it was all okay and that it was different water supply. They told my dad when he was working with them that it was a different water supply, that it was fine, that it was perfectly safe. The clinical staff were under the impression it was a completely different water supply. It was us that told Dr Sastry that it wasn't.

167. When I was first diagnosed, I was told by staff to run the shower for three minutes before I could use it. There was a sign up in all the bathrooms saying this. On the days that the water was switched off, we weren't allowed to use the shower if they were doing something to the water. We were told a couple of hours in advance that the water was going to be switched off, and if we wanted to shower to do it before then. The staff gave us the hospital grade wipes for patients to use when this was happening. You don't really feel clean if you just wipe yourself though, it was not nice. The water was often switched

off in 2A. There were times we weren't allowed to use the showers and I couldn't flush the toilet.

## **OTHER OBSERVATIONS ABOUT THE HOSPITAL BUILDING**

### **Hydrogen Peroxide Vapour ("HPV") cleaning**

168. The hospital did hydrogen peroxide vapour ("HPV") cleaning on the wards. During the summer of 2018 when I was an in-patient on ward 2A with the bug, I was moved from room to room as they blocked off the rooms to do HPV cleans. The staff made sure that people were not on the ward unless they absolutely needed to be. I was so unwell and I had to stay on the ward so I witnessed what was going on. I was moved from room to room as the cleaning was done throughout the ward.
169. When the HPV cleans took place, a machine was put in a room and then the rooms were sealed off with orange tape to stop any fumes getting out just because of the type of patients we are. After a period of time the room was unsealed and they'd move onto the next room.
170. I knew that I was being moved so the cleans could take place. I wasn't aware why they were doing it, I just knew they had to do it. We got a letter explaining that they were going to do this clean and then the lead nurse again came round to speak to us. The first time it happened, I was moved right away. When the cleans were going on, we just didn't unpack. Eventually they moved me back to my room, it was the room that I was always in, which was room 6 in Ward 2A.

### **Cladding**

171. We also got a letter at one point about the cladding on the outside of the building, we were no longer allowed to use the entrance to the RHC due to fungus in the cladding. We weren't allowed to use the main entrance in the adult hospital because the windows were falling out. We had to go and use
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the door at the discharge lounge, that was where everyone smoked, but that was the best option. It was either walk in through the cladding that had all the fungus, walk and have a window fall on you or go in through smoke: so we chose the smoke.

172. I received the letter about the cladding. I think it was when I was an out-patient and visiting the day-care in ward 6A. I got given the letter then.

### **Windows**

173. I was getting the taxi back from radiotherapy at the Beatson when I was an in-patient in the RHC, while I was still receiving chemotherapy. I came out the taxi in my wheelchair and a window had fallen out of the building in the QEUH. The glass was everywhere on the ground. When I was going into the hospital building in my wheelchair, the taxi driver stopped and he lifted the wheelchair up and over so that I could go round rather than my wheels going through the glass.

### **COMMUNICATION**

174. Clinically, the staff's communication was always incredible. I could never complain. It was with the management that I have witnessed issues in not being upfront. I feel like they don't learn, even to this day. Some communications are insensitive and very generic. They just don't quite seem to understand that it's real people they are dealing with.

175. When the Oversight Board report and the main Case Note Review Report was published, patients and families received a letter from the Health Board. Everyone that had been a patient since 2015 received the exact same letter: so whether you were still in treatment, you were out of treatment, the patient was now over 18 and you're receiving the letter yourself, or if the child had passed away - everyone received the same letter. The letters were written to parents about children in the present tense, it was completely insensitive. A lot of these children didn't make it and were no longer here. I was annoyed as

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they wrote to me as if I was a parent, but when you compare that to writing to parents as if their child's still there - it's horrible. In my opinion it's unforgivable to put someone through that when they're already suffering enough.

176. There's a closed Facebook page between the hospital and families and I am now old enough and am allowed to be on it. I used the page to make it very clear to the hospital about how I felt about the letter that was issued to families. I received a letter from the Chief Executive apologising which was wholly inappropriate as she addressed the issue as if the biggest thing in my life was COVID. The response had the line "hope I am keeping well in these strange times". COVID is not the biggest concern, cancer is. I feel as if they don't seem to get that it's people at the centre.

177. In terms of the closed Facebook group, I don't know about the impact that it has had. Sometimes the administrators could do a bit more with it, for example how they communicate and answer questions. I understand that that's not their job necessarily but parents are obviously stressed and they've been told that that the Facebook group is their way to communicate with the hospital. The page administrators need to communicate to the clinical staff what people are saying in the Facebook group. Sometimes the clinical staff aren't aware of it and that is causing a breakdown in trust. It's a bit disjointed. I am aware of a few times where people have been stressed unnecessarily because a message posted on the group is not passed on right away to clinical staff. Maybe it's because it's not the right place to put it, but that might be a good thing to communicate to people. There seems to be an imbalance, whether or not that's the right place for people to put these kinds of medical worries. The hospital needs to tell users rather than have this in-between stage which is where we are at now.

178. I am not exactly sure who runs the close Facebook Group because different people answer at different times. Sometimes Professor White would maybe put an update on behalf of the Oversight Board but other than that it seemed to be the communications and engagement people from the Health Board that answered. I think there were a couple of times when Craig White had posted

an update but I think someone put it up on behalf of him rather than him running it.

**Communication: the move from ward 2A to ward 6A and issues on ward 6A**

179. I was admitted to 6A in the October 2018 after ward two 2A closed. I was discharged from ward 2A at the end of September 2018. The decant happened over a weekend and then I was admitted to 6A for chemo during the first week following the move. I found out that the Schiehallion ward 2A and 2B were going to be closed when the staff came round and told me, we got a letter. I believe at this point management spoke to us as well, they came round with the lead nurse and the nurse in charge. What they said was that ward 6A would be a lot better, that the issues with the Children's Hospital were not issues in the QEUH, and we would be fine in the Queen Elizabeth. But when we got to Ward 6A there were filters on the taps, we weren't allowed to drink the water from the taps and we had to use bottled water. The hospital staff did HPV cleans all the time.

180. Sometimes maintenance staff would come and test water, change the filters, the sink traps and they would do deep cleans so the rooms would be shut off. I remember there was mould in the staff kitchen in 6A and we weren't actually told it was mould by the higher-up staff, we were just told that they were rejigging the staff kitchen. The auxiliaries told us, we were quite close with the auxiliaries and the cleaning staff as well. Latterly found out that that was the case.

181. When ward 2A and 2B were closed, the hospital said that they had to fix the problems so they were going to take stuff out and refit the ventilation and everything and make sure that it was safer for us to be on. We were told it would be a couple of months. We're still in 6A now. At the time they thought that we would be back in 2A in the new year of 2019. I understand that the ventilation was fitted backwards, or that it was blowing out the wrong air rather than taking it away. I'm not an engineer. My dad seems to understand it all a lot more than I do, this is more his remit.

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**Communication about issues with the building**

182. As regards the water we got some letters on the wards and it was also in the news, so if you watched the news you used to find out. We knew there were issues with ventilation because of letters we received from the hospital and because of things in the news.

183. In terms of communication about the issues with the hospital think it's slightly improved since I was treated there as in-patient. I still feel that we still don't have answers. It is different now to when we used to find out what was happening from the news, but we still don't really know much at all, so you can understand why we were stressed.

**Communication: Healthcare Associated Infections**

184. Dr Sastry was never as blunt as saying "This is where you caught the bug", but he would vent his frustrations with issues with the hospital. I remember one particular time in May 2018, he came into my room on ward 2A and he was really angry. He is not a man that gets angry, he's got a gentle manner. He had gone to use the toilet in day-care and no one had told him that they'd switched the water off, and it took him five rooms to try and wash his hands; he was appalled. He was really strict about handwashing, it had to be done a certain way. He watched people like a hawk to ensure they washed their hands, when they came into the room, especially if they were doing a check-up on me. If he was not happy with how they washed their hands then they do not go near the patient. He never said anything that in front of the patient but he'd always speak to people outside. The fact that he had to go to five different rooms to try and wash his hands, he was absolutely appalled and he told us there was no communication between the hospital and the staff and the staff didn't have any idea. He was very angry. I think he wanted us to know because we were doing something about it, or certainly my dad was trying to do something about it. But he has never been as blunt to say "This is where I think you got the infection." I have however had a letter from the Chair

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of the Board apologising for a hospital-acquired infection, it was sent to my dad on 4 September 2018. My dad can provide the letter.

185. When I had the bug for the second time in October 2018, I spoke to Dr Christine Peters. She took over from Dr Teresa Inkster as my lead microbiologist. In October 2018 I requested a meeting with Doctor Peters. As I was over 16, I requested that I be there and she came to my room with Dr Sastry and I spoke to her along with my mum and dad, whereas the first time I had the bug, Dr Inkster only spoke to my mum and dad in June 2018.

186. Dr Peters was very frank, she said that she didn't know whether it was going to work or not. She explained that the bug was resistant to the antibiotics that I had the first time so they needed a new lot, explained that when she'd spoken to Professor Lawrence again and if those antibiotics don't work, they'll find more. If they could find more, they would. She was upfront, which I appreciated, because I'd rather know that they don't know than have them cover it up.

### **THE INDEPENDENT CASE NOTE REVIEW**

187. My dad can tell you more about this. When I first received my letter sending me my individual report, at the section where it addressed whether they were answering any points raised by myself or someone from my family, it said that they hadn't received anything. But that was not the case. Right at the start of the review, my dad had sent the panel a long report on my mycobacterium chelonae. It was to be passed on by other people and it turned out it was never passed on to the panel. I emailed them back and then they had to reconsider their final report based on the information that they should have had from my dad in the first place.

188. As regards my individual report, it's a bit disappointing that they cannot categorically make conclusions but I was pleased with my report in the sense that I felt that it was really clever. The report explained that if samples had been taken at the correct times that we would be in a very different place. It also explained about how samples that had been found of mycobacterium chelonae had been previously found in rooms that I was staying in a lot of the time leading up to the period when I got the bug. Further that perhaps if the hospital had looked at the time I had got the bug they might have found it. The biggest thing for me was that the report also said that I wasn't the first case, but we were always told right from the start that I was. But there was a case earlier than me, and so that damaged my trust in the hospital for a while.

189. I'm still very angry about it. I feel that if the hospital had any knowledge that it could have used it should have, and had they told us about another case I think we would have pushed even harder for the samples to have been taken of the ward. But the argument at the time had been that I was an isolated case and there was no need to do that. It created a lot of uncertainty for me, I don't really know what I can trust anymore when it comes to the circumstances of my infection.

190. I am planning to meet with Professor Stevens and his team. I couldn't have my meeting right away because of exams, but he said that he would keep the time for us and we've just to organise that and I will do that. I'd like to meet them along with my dad to discuss more about the report and certainly to find out where that information came from, because as far as Dr Sastry was aware I was the first patient. I do trust Dr Sastry, and I trust that he would have told me because he told me when someone else contracted it after me.

191. As regards the overall main report, it was a hard read. I was really upset at the findings that two kids died and at least in part it was as a result of hospital-acquired infections. I just think that's horrific, two kids had passed away. Even if it was just in part, it's completely unforgivable. To think it could have been prevented, I can't even imagine how the families are feeling.

192. I was appalled at how many of the cases were suspected to be linked to the hospital in some way. At first, at the very start when I first got sick there were around 21 or 22 cases reported and now it's 84 cases with over 118 incidents: the majority of them with possible or probable links to the hospital. I think it's only 7 or 8 where it has been ruled out that they aren't to do with the hospital. It is hard enough to manage what we have to deal with without having to have all that on board, because the place that's supposed to make you better was actually making you worse.

### **CONCLUDING REMARKS**

193. As regards the hospital, I was very glad to move to adults because I'm now based at the Beatson in Glasgow. If I can, I'll avoid going back to the RHC and QEUH as a patient. I find it okay to go for scans, but I don't really want to go for anything more than that, if I'm honest. I hate that it's come to that because we're doing so much for the ward with Every Thank You Counts. It's such a happy place and it's going to be a happy place, I know it will be when it's all fixed, but it's tarnished for me now. After putting in so much work for the facility, it's horrible to think that but it is.

194. It's something that comes up a lot when I speak with my psychologist. For quite a while I didn't even want to be a doctor because I didn't want to work with a health board because of my experience. This is an ambition I had since I was a kid, and it was ruined. I worked so hard whilst being sick and it felt it had been for nothing. I'm eventually coming round to the idea and I understand that I don't have to work for the NHS, maybe I'm being a bit precious but the best way to describe it is that I don't feel comfortable.

195. The Health Board need to remember that there are patients involved. We are live patients, and we are at the centre of it. People make mistakes and that's fine, and if people held their hands up and said, "Look, this happened, we're sorry, we're going to fix it", that would be fine. I'd be a bit angry but I'd get over it. But things are constantly coming out about what has happened, for example that this sample wasn't taken or it turns out someone had the bug

before you and you weren't actually the first person to contract it. I understand that there's no singular person responsible but I don't trust them because of this; it's the only way to say it. It's horrible to think that I don't trust something that I am going to need for the rest of my life, because I'll never be out of hospital. I'll never be done with it because of all the side-effects I've been left with; all the issues in my different organs. I will always be in and out the hospital and to think that I don't trust the Health Board is quite frightening.

196. In terms of addressing how I feel, the best thing best thing for me is to know more about it. Getting answers: this is what's happening now with the Public Inquiry. Uncertainty is probably the worst part, not knowing what's happened. Anything that can be found out is a comfort. For the families of those two kids, anything that can be found out could give them a bit of justice.

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