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Witness Name: Rachel Gordon-Smith

Statement No.: WITN2633001

Exhibits: WITN2633002-004

Dated: 5th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF RACHEL GORDON-SMITH

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated the 25th March 2019.

I, Rachel Gordon-Smith, will say as follows: -

Section 1. Introduction

1. My name is Rachel Gordon-Smith. My date of birth is the 10th September 1965. My address is known to the Inquiry. I am unmarried and I have no children. I have spent a lot of my working life working with the elderly as a nurse. I intend to speak about my Dad, Randolph Peter Gordon-Smith (known as Peter) who has born on the GRO-C 1940 I intend to speak about Dad's infection of hepatitis C, which went onto develop into hepatocellular cancer. In particular, I will talk about the nature of his illness, how the illness affected him, the treatment he received and the impact it

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GRO-C

had on him and our lives together as a family up until his death on the 24th July 2018. I do not wish to be anonymous for this statement.

2. My sister, Justine Gordon-Smith, has also given a statement to the Inquiry about our Dad's infection and his death. I have tried to tell my interpretation of our story to the Inquiry and avoid unnecessary repetition of the details of my Dad's story.

Section 2. How Affected

Dad's haemophilia and treatment

3. Dad had Haemophilia A, the severity of which varied. It could be mild, moderate or severe. It varied all the way along the scale over the years, partly depending on what the Scottish NHS had decided the criteria was for that year as they did vary the goal posts. The severity did also vary, particularly after 1993 according to how badly Dad was affected by his factor VIII inhibitor. There were points later on in his life when he couldn't even have a slight tap without having a bruise/swollen lump appear. Prior to the inhibitor, he was probably mild to moderate or mostly moderate. Dad's own factor VIII levels had a variation of their own. Sometimes in the winter this would be the worst time for him, but not always, I knew that between the months of February and April that there could be issues then with bleeds, but that didn't mean he wouldn't injure himself in between times.

4. Dad used whatever product was available when he attended the Royal Infirmary Edinburgh (RIE). When he was a small child I understand that he may have been treated snake venom, then whole blood or cryoprecipitate. At some point, in the early 1970s factor VIII concentrate was invented and eventually synthetic factor. There are letters that my sister has provided to the Inquiry which indicate the treatment Dad was receiving.

GRO-C

5. As a document from February 1994 which was compiled by my Dad shows (exhibited with Justine's statement) there were times in the 1970s when there was a threat from hepatitis B and in the 1980s once the threat of HIV became apparent, that my Dad and the rest of the haemophilia community were very alarmed that the NHS were importing blood products from America because it was cheaper. Dad had discussed this with the staff at the Haemophilia Centre in Edinburgh and he always thought that Scotland had become self-sufficient as soon as they could. Dad always thought the Scottish stuff was better because they made it themselves. In any event, he tried to avoid using concentrates.

6. Dad knew that if he went into hospital that there was a risk if it was a really busy weekend, he could end up getting imported product. There would not be a conversation where he would be told they were using an imported product. Dad just knew that there was this risk and that it could occur. This is one of the reasons he avoided having treatment as much as he could in the 1970s and 80s.

7. There was an earlier point in our lives between 1970-1974 where we nearly moved to Suffolk, England and according to Dad's preferences, it was agreed that the hospital down there would get him Scottish treatment if we moved there.

8. Dad would always ask lots of questions about products which became available. There was even a point he was having home treatment in around 1997. He always took a good level of interest in what they were giving him. Having read a lot of these letters and knowing Dad's reaction when he found out that he was infected, it was clear to him that people at Edinburgh Royal Infirmary (RIE) had lied to him, mainly Professor Ludlam and the Registrars but all landing on Professor Ludlam's head ultimately as he was responsible for Dad's care.

GRO-C

9. I believe that at some point in the 1980s that the products he was being given were contaminated. Both I and Dad felt that there was a good chance that his infection could have been avoided with more care. He did not receive much treatment at that time. He always wanted to take treatment only when he could be sure it was safe.

10. Dad would mention his concerns to Professor Ludlam and his staff and they would always reassure him and say not to worry as they only used a local product. From 1986 there was this vast and extremely depressing AIDS campaign. It was on the TV all the time. It was even on the BBC. Dad watched a lot of TV and he followed this news and the fact there was this product from the USA, which came from convicts and drug addicts. It really upset him that people like him were at risk, that the Government was so callous that they deliberately took this risk. He always felt that there should be proper screening on the treatment the medical profession were giving to people to make sure it was safe. I don't think if Dad had known that he was being given a product that potentially could have had hepatitis,. he would not have accepted it if he had known there was a risk. I think he would have rather died of his injuries than suffer a life limiting infection for the rest of his life. If he had been told, you can have this product but there is a chance you could receive a chronic infection, he would have never have accepted it. He would have toughed it out.

11. The Royal Infirmary Edinburgh (RIE) was the main place Dad was treated, but in 1997 they moved some of his treatment from the RIE at ward 23 to the Western General, Edinburgh (WG), ward 8 as they decided to amalgamate all the people with blood disorders in one place. This was the age of the NHS Trusts. They thought it would be more effective to have everyone in the same place because it meant all the consultants could be at the same place. The fly in the ointment for that was that the Haemophilia Centre was still at the RIE, but all the inpatient treatment was at the WG. It meant that all the haemophiliacs were going in and meeting people with leukaemia and other blood disorders.

GRO-C

The haemophiliacs eventually complained because they were meeting all these people, making friends and all these people were dying. It really upset them because the thing about haemophilia as far as Dad was concerned was that it might make life awkward and you may have to spend several weeks in hospital every year, but 80-90% of the time you could live your life. It in itself was not going to kill you. He hated forming attachments with all these other people who were dying. He never wanted to be in that situation but essentially that was what happened to him in the end. The whole treatment stayed at the WG for a while. The haemophiliacs complained, but due to costs they didn't get their own way for a time. If memory serves, it may have moved back to the RIE in the year 2000, and then moved to ward 25 and then to ward 207 at the new RIE.

Dad's knowledge of his hepatitis C infection

12. Dad was infected with hepatitis C, genotype 3. The doctors never told him exactly when he was infected, but they finally told him at the end of 1993/ start of 1994 that he was infected. Dad was married to Patricia, his 3rd wife at this point. I remember him being very upset when he told me. He had had letters from the hospital requesting to see him, so he had gone up to RIE and was told between November 1993 and January 1994, about his diagnosis. Dad wrote a letter in February 1994 to the hospital. Again, this is provided to the Inquiry through Justine's statement. Dad tried to pinpoint when he was infected. He was quite well you see. He wasn't in hospital much for a haemophiliac, not that often between 1980 and 1989 compared to subsequent decades. He pinpointed the treatment he had received. He did not receive any response and when and how he had become infected despite the advice he had received over the years about the safety of the products he had been given.

13. There were two incidents within a year of each other in 1989 when Dad was beaten up, which led to him requiring to have treatment. (the 1988

he had to have the product and was intensely worried about the risk. The AIDS campaign was still ongoing at this time and he was worried about how rigorous the testing was. He was worried he might receive a product from America or something but the Haemophilia Centre, Edinburgh would always reassure him that it was local. We have never had it confirmed that Dad has received American factor.

14. It was GRO-D at the RIE who told Dad he was infected. Dad was extremely upset and devastated they had done this to him. He had suspicions that the doctors at RIE had tried to use a product on the cheap or something. He was always worried about the treatment and in particular from the point it had started to be imported into Britain from abroad.

15. The information he was given was not adequate. He didn't see this at the time, he told me this later though. He was given what information he needed to live his life at the point he was diagnosed and no more. So he was told to moderate his alcohol intake severely for example. No more than a couple of pints a week or something, but he wasn't told that there was a chance he could get cancer or that his health could otherwise deteriorate. He knew he should use condoms. He was given some information about the risk of spreading the infection but not enough. He and I didn't really talk about that kind of thing.

16. He should have been told a lot sooner than when he was that he was infected. I am sure that he could have been. Dad eventually decided in his own mind, that this was some accidental thing that had happened rather than anything else. The doctors should have told him the circumstances of the infection and they should have told him of the existence of the virus the minute that they knew. Our concern is that they may have known that the products carried a risk of infection and yet they chose to give him the products. If they knew and could have avoided giving him the products without risking his life, they should have never given them to him. They should have given him an

GRO-C

have never given them to him. They should have given him an alternative to keep him safe or a blood transfusion or something to keep him safe and not done what they did. They should at least have told him about the risks and he would never have taken them.

17. He felt extremely betrayed by what the doctors had done to him. The thing that bothered him was that he never knew what to expect from hepatitis C. All he knew was that he had to avoid irritating his liver to avoid making him ill. He knew later, much much later, that there was a risk of cancer.

18. The doctors were extremely insensitive, I believe this because of his reaction and, as I say, his feeling that he should have been told a lot sooner. The dishonesty always upset him. Initially he thought it was an accident and it wasn't Professor Ludlam's fault. Professor Ludlam had always helped Dad and did a lot for him. Dad later realised that this was out of guilt. Dad was very upset for a long time about that when he realised. He did however forgive Professor Ludlam, despite how awful it was.

Section 3. Other Infections

19. Apart from the hepatitis C, Dad was not otherwise infected. I know this, because Dad was in hospital in 1997 after a rather nasty bleed in his knee. I went to visit him at ward 8 one night. There were a lot of children in the ward visiting people when I did, there was even a dog running around. Dad's bed had been moved and next to him was a sharps box with all sorts of things on top of it. I thought, that I had to do something about it, because there were children everywhere and no staff were available. So I popped on surgical gloves and picked up all this stuff. I went to take it out and this butterfly, which is a type of infusion needle, span round and broke the glove. Once I got rid of the rubbish I went and found the staff and reported it. This meant I had to have 18 months of testing and Dad was tested as well because of the situation we were

GRO-C

in. I was told through this, that it was just hepatitis C that Dad had. He may of course have been exposed to other viruses which they could not test for. This also implied that Dad had been tested for other viruses without his knowledge.

Section 4. Consent

20. Dad had hepatitis C and was tested without his knowledge or consent. He was treated with the products and reassured that they were local products, having his fears and concerns downplayed. He was not told of the risks of the local products, merely told that they were not imported. Therefore he did not give his consent as he was not fully informed about what he was getting. It also follows that he was not given full information about the products he was receiving.

21. I think that Dad has been used for research. I believe they did not tell him for years about the infection to see how the hepatitis would develop for Dad. They did not told him about any of the other symptoms associated with hepatitis C. He was only told to moderate his alcohol intake.

Section 5. Impact

22. For the first few years Dad after was diagnosed in 1993/ 1994, he was just a bit depressed and he had to see a clinical psychologist. He took anti-depressants, but also concurrently from 1993, Dad developed an inhibitor. Dad initially wanted to sue for having developed the inhibitor but he was blocked all the way and told he had no chance by solicitors and that it would be incredibly expensive. In the end he didn't. I know if he could have got some proper no win no fee representation he would have done it and taken them for all they had.

23. At the time, the inhibitor, more than hepatitis C, severely affected his life. The hepatitis C was more severe after the inhibitor developed. He

GRO-C

nearly died in 1993 because of it. He had had a lot of problems with his knee at the time and prior to receiving a procedure on his knee he received a continuous infusion of factor VIII. Dad watched his infusions very closely and he had cellulitis which turned into phlebitis and his body started to react to the infusion. His body decided that the factor VIII was bad so his body started to try and fight it and he developed this inhibitor. This meant for a long time Dad had to have FEIBA (factor eight inhibitor bypassing activity). The combination of having this and hepatitis C made his life miserable. In that period, the hepatitis C seemed to be less of an issue than the inhibitor but I think both the inhibitor and hepatitis C were working against him at the same time.

24. Later the hepatitis C seemed to affect him more in all kinds of different ways. Dad's levels were checked regularly and Dad always got very upset when his inhibitor levels were up. At some point in 2016 his levels went right up again and then he got the cancer diagnosis. He hated having hepatitis C. Hated it with a passion. He sincerely wished he had never been infected in the first place. He would have had a more productive life if he hadn't been unwell. He wouldn't have given up his job if he hadn't been so unwell. His life would have been completely different without the hepatitis C and he would have been a much happier man.

25. Dad was tried on some treatment for his hepatitis C. His liver was investigated on around 3 May 1995. He was told that he could be out on Interferon therapy. I exhibit WITN2633002 [exhibit medical records pages 276 and 277]. He had a sort trial at treatment but that was discontinued because of side effects. Further treatment with Interferon and Ribavirin was discussed with him on 12 February 2003. I exhibit WITN2633003 [exhibit medical records page 121] and again on 10 August 2004 which I exhibit WITN2633004 [exhibit medical records page 129]. He did not have that treatment. None of these letters appear to make it clear that if he did not undergo the treatment that this could get worse and that he could develop cancer, as he later did.

GRO-C

26. Having liver cancer was awful and the hepatitis C made him miserable. His only hope when he discovered he had cancer in December 2016 was that the Transcatheter Arterial Chemoembolization (TACE) would work. That was the procedure he had in February 2017, that was his only hope. When it didn't work, that was when the downwards spiral really started and it was all because of the hepatitis C. Dad forgave Professor Ludlam under the conditions I have said, but he would have rather not have had it in the first place. He would have preferred if they had avoided putting him in that position in the first place.

27. Dad's cancer when it was diagnosed was stage 3. We were all told at the beginning of December 2016 that Dad had this and that it could be terminal. There was a chance of catching it if he went forward with TACE however. There would probably always be a risk but if they caught it, he would have more time. I think even taking that into account, he should have had the TACE not just when they thought they had time, but right then, from the moment they realised. They should have not waited 2 months because in cancer, every week counts when you are trying to stop something. It is only in a situation when you are 99% sure that something is very slow growing that you have more time. In something like what happened to Dad you have to strike when the iron is hot. I feel because of Dad's age, he was in his 70s, they didn't do the procedure as quickly as they would have done, if it was someone younger.

28. Dad was annoyed he had to wait. I feel he shouldn't have been discharged until it was done. At the very least between Christmas and New Year and at the very most the first week in January, not in the 2nd week in February. Because of that extra wait, the cancer grew and spread out so they didn't catch it all. Liver cancer of that kind is a nasty so and so, it is quite insidious. It doesn't expand quickly but it grows faster than you think. They should have treated him differently. It would have helped him a lot, but the fact he was put in that position in the first place is unbelievable.

GRO-C

29. The day he had the TACE procedure at the WG, I had to work. It was really unfortunate as my rota had already been drawn up for work when the appointment came through and due to the nature of my role, it is not something I can change with ease. Justine was available and she went and sat with him. I was checking my phone every chance I got and I'd see all these messages and I'd think "*Oh God, poor Dad, poor Justine*". He went through such agony and I just kept thinking, "*Oh please let this be worth it, please let him be better*". He had a horrible week in hospital. We made him stay in an extra few days, he was so ill. When he was discharged he was sent home with no care package, no support, he was behaving like a confused old man. It was a bloody struggle. The hospital expected us to carry the bags, walk out of there and expect him to walk all the way downstairs. Eventually I managed to get a porter and a chair but it wasn't easy and they were very grudging. As I got him to put his coat on, he was so delirious from everything that he insisted on putting his coat on backwards and when he saw what he had done, he blamed me. That wasn't very nice.

30. We left the hospital. I took him to Justine's house and he was very grumpy. He slept a lot then and when he was awake, he was in such a state, he was also unable to do anything for himself. After the TACE procedure, for the first few months he was fairly stoic. He enjoyed life when he could. What he didn't tell us, for a long time, was that he had already tried to kill himself with a plastic bag over his head. Somehow it hadn't worked or he deemed it pointless, but he didn't tell us for a long time. That was hard. He was still behaving to us normally, but with more support. After he had got over the disappointment of TACE, Dad needed a lot of repeated visits to hospital. It tailed off after for a while and it wasn't the intense care that it eventually became, but we did have to keep an eye on him. By March/April 2017, we had to put him on a dossette pack because he kept forgetting to take at least one lot of his tablets every day. We knew by then though that things could get considerably worse. It was around that time that Justine and I started

GRO-C

to try and get a care package set up. It was mainly Justine but I was also involved. It took weeks! Absolute weeks!

31. Dad had issues with his bowels from the year I was born. He fell off a lighting gantry at the Kings Theatre and his rear end was impaled which had left him with issues with his bowels for many years and left him with severe toileting issues towards the end of his life.

32. Dad was quite depressed about going to the toilet. This had been something that had always been an issue, ever since his accident in 1965. We eventually managed to arrange a bidet toilet to be installed. He was very happy about this. Then in May 2017 we went to the RIE for two appointments in one day, with an hour gap between the two. We went to the first appointment and we were told that the appointments shouldn't have happened so close together, because the 2nd appointment was for a surgeon to confirm what the first appointment was about to tell us and discuss his options. At the first appointment he was told that the TACE hadn't caught the cancer completely. At the 2nd appointment, the oncologist told Dad of a possibility of another treatment that could help. He gave Dad a week to think about it. Justine, Dad and I were shell shocked. Dad decided he wasn't sure; he was in two minds about what to do. So he went along to discuss the options and the surgeon basically said *"you can't have it, you are a haemophiliac it is too risky. Go and get on with your life and if you need anything let us know."* Dad and I were devastated. We tried to keep things normal for him, but it was hard. Dad finished sorting out his will, and that was tough. We felt completely let down by the NHS at that point.

33. There was no follow up from palliative care at that point, we were just left in limbo. Justine got onto that asap and got things arranged with Marie Curie. Because of my work, I had a long standing professional relationship with Marie Curie, so I thought it would be ok. I quickly learned how useless the nurse we had been given was. Dad hated the

GRO-C

place, he said it was a "*Citadel of twee*" and it really gave him the creeps. It was like a death factory. Yes, hospices are places for respite or somewhere to go to die, but they should be calm, peaceful, welcoming places, they shouldn't feel like death factories. That one did. Dad at that point was starting to experience regular nausea, but he fixated on the idea that the cancer had grown. His GP and the cancer nurse came to see him fairly regularly, and he would go on about this.

34. Eventually the cancer nurse suggested steroids. He at that point had never taken steroids before and was presented with two opposing situations. I was always ok on steroids that I had taken due to asthma, but Justine is very sensitive on them, it causes issues for her. Dad's immune system is closer to hers than mine. He still made the decision to go for it. At first he was great on them, but by the end of the week on the 8th June 2017, he was anxious, delirious and in a state. I thought he must have an acute infection he was so bad. The doctor came out and decided that he was anxious and gave him diazepam to calm him down. I wanted him tailed off the steroids then, as you can't just stop steroids suddenly, but it didn't happen quick enough. The Marie Curie nurse came round the following week and Dad sat there in front of me behaving totally normally so she said carry on, maybe go on a lower dose. Dad at that point still had capacity so it was his decision but I wasn't happy. The following week, Dad attempted suicide.

35. The day of the 1st suicide attempt, Dad had left a note out for the carer saying that he had gone to hospital. So I phoned Dad and he said "*I don't want to see her, I just want to sleep*". So I said "*Ok you have a long lie, but I'll be round in the afternoon*". I went round in the afternoon, and he was sitting there in his pyjamas looking sad and withdrawn. I looked at him and asked, "*Do you need your tablets, you look a bit strange*". I went to his bedroom to check as he was on dossette pack at that point. When I did, I saw the empty bottle of oramorph. I then realised that he had also had spare tramadol and he had basically taken 34 tramadol as well. I am very experienced in my line of work and

he was sitting there conscious. If someone is sitting there conscious after something like that, the first thing you have to find out is when did they do this. He then told me he had done this early in the morning. This was 2pm at this point. I thought ok, he does not need an ambulance, he wasn't in any immediate danger. He had built up a tolerance, but he also had a constitution of a rhino. I was astounded by it. I knew people who would have been unconscious on a third of that. It was a new bottle as well. You get about 100ml in a bottle and a dose is about 2ml and he must have had almost 98ml left.

36. We had a fairly frank conversation and I said "*I have to phone the GP; I have to tell them*". I agreed not to phone the ambulance, because he was conscious so it was not required at that very moment. I phoned his GP, told her what had happened and she agreed, he was not in any immediate danger. She presented two choices. He could go to Accident and Emergency or I could watch him. The GP came round that evening and persuaded him that he should go into the WG for observation. I wish he had gone somewhere else. It was terrible. At first Dad was absolutely pain free, due to the amount of analgesia he had taken and remained so for 2 days. Then he had horrible problems with his bowels. Unfortunately, where he was, he had a single room but no en suite bathroom and the hospital hadn't thought to get a commode next to him which was silly because they knew what was coming. When it did, it was horrible for him, the staff were sweet and did change him and things, and Justine and I managed to lobby to get him moved. He got a lovely room with a beautiful view but he didn't like it. He didn't like the fact that the sink was too far away from the toilet. It was too different from the layout of the RIE that he was used to. He started plotting to get out and started phoning my sister Julia telling her to come and get him and not tell us. It was like an escape from Alcatraz. He saw a psychiatrist who said he was of sound mind and released him

37. Then he was put on fentanyl before discharge. The first few weeks he was fine on it, but he kept wanting more. He kept saying his pain level

GRO-C

was worse. The doctors kept believing him and increasing the dose. I now know, it was him trying to get enough prescribed to fall asleep and not wake up. He started behaving erratically again like he was still on steroids. We persuaded him to go into the RIE under the care of Dr Anderson for a week. He did but he was in a terrible state for that whole week. It was so strange. I would get him to leave the ward and go for a cup of tea and he would start acting like Dad again. The minute I got him back to the ward he would change back to this other person again. We used that week to have his specialist toilet installed and got it all ready. When he was discharged, we brought him home and he went to use it for the first time. When he came back out he had a face like Private Fraser from Dad's Army. He was so sullen, it just made Justine and me miserable. He developed a love/ hate relationship with the toilet from then on. He couldn't have it removed. It was very expensive. We got him to persevere with it. We know now that part of his behaviour emotionally was the consequence of the hepatitis C.

38. I will never forget about the 2nd suicide attempt on the the 24th September 2017. I had had a busy morning at work. It was about 11:30am and I checked my phone and was about to go for my coffee break. Then I saw a message from Justine. She knew not to phone me and leave a message unless it was really bad. I saw the message sign on my phone and thought *"oh no, what has he done?"* I was hoping he had had a stumble and had to go to hospital with a bleed which would have been preferable compared to what it turned out to be. I phoned her and she told me that Dad had made another suicide attempt. This time there were 3 bottles of oramorph in the sink. I felt worse in that moment, than I did when he died because when he died, everything was peaceful. He was surrounded by his family and there was a lot of love in the room. I made sure that he departed in peace and serenity. At that moment, it was worse because I wasn't ready to lose him. I had the most incredible feeling of loss and my whole world felt taken away in that moment. I was incredibly sad.

39. My colleague was thankfully able to get another member of staff to take over from me so I could leave. The problem with my line of work is that you can't really down tools and run. That day I think I was out by 12 noon though. I got to the hospital at the point Dad started to wake up. The look of betrayal he gave us, was horrible. I said to him "*Look Dad, you left the empty bottles in the sink. There is a bin next to the sink, that means that subconsciously you wanted to leave it to fate. You wanted to have a chance of being saved*". He did get it. My Mum came up to see him when he was in the WG and they were wanting to section him. Mum was telling Dad what to say and what not to say to the doctors and of course he then said the wrong thing to the psychiatrist and we had to fight them to stop sectioning him.

40. I remember the day Dad tried to stab himself as his health just continued to decline. I had just let the podiatrist out as the home care worker had arrived and we just looked on him and then had a brief chat in the sitting room before she went to attend to Dad, who was in his room. She went through about a minute later, and instantly called me. I went through and saw that Dad had stabbed himself with a small pair of nail scissors that I didn't know he had. Every other pair of scissors in the house was in the kitchen. Somehow he had got hold of these. His care worker was holding a cloth round his wrist, so I made the injury safe enough and dressed the wound. I made the bandage quite tight to stop the bleeding but then Dad started complaining about compartment syndrome, because the bandage was so tight. I had to undo the bandage, slightly, and he accepted it, but was very grumpy. As soon as I had done this, I phoned the Haemophilia Centre and arranged for him to go. His PA arrived and I had done such a good job with the bandage, the hospital left him sitting in the waiting room for nearly an hour. Then he went through and saw Dr Rodgers, who had a look at the wound and confirmed that Dad was going to need stitches. He went to get some FEIBA, which ultimately meant that it had been 3 hours from injury to treatment.

41. We went round to Accident and Emergency and saw a psychiatric registrar. It was like a student really; like a a kid with a clipboard. They knew he was safe because I had done a good job and he had had his treatment. So they made him wait even longer until after 5pm. I had to stay with him that night and I asked him why. He told me he felt paralysed at that moment, as the podiatrist had made him do something to avoid a pressure sore developing and he didn't want to co-operate. She hadn't explained beforehand why she was doing this, because she was in such a rush. It is a very serious thing to get a pressure sore, in fact if a patient develops one now, it has to be reported to the Care Inspectorate. It must be avoided. I explained the reason and he was accepting when it was explained.

42. I had just got through that and the following day, Justine came round. Usually when she did take over, I would hang around and have a cup of coffee, but that day, I practically ran home, cried and then went down to my Mum's for a couple of days. But I still had to come back and look after Dad at the weekend. It gave me very little pleasure to do so and I did it entirely out of duty. That was the only weekend where I attended to him only out of duty. It didn't affect how I cared for him. It didn't affect how much I loved him but it was the only time it was only out of duty that I went. We loved Dad so much but he was very much hard work. Our entire lives revolved around him. The cancer and the hepatitis C which caused it took Dad away. It robbed us of the person he was.

43. This is a poem that I wrote that describes how I felt. It is called *Dad and Joan*.

I hate Dad in the morning
Nothing is ever right
He stares at me contemptuously
And starts to pick a fight
He seems to be Joan Crawford

GRO-C

And his manners are the same
All tortured and incandescent
And on a higher plane.
By lunchtime things are better
And sunshine might appear
He's more polite and civil
And thankful we are here
I love my dad at bedtime
The clouds is a happy place
He is always sweet and wonderful
His smile is full of grace
He goes to sleep so peacefully
All matters put to right
But somehow
I know that Joan may come
Like morning follows night.

That is, in summary, what every day was like. You would get the odd time where somehow he had a better night and be ok, but mainly it would be like this.

44. Towards the end of his life in June 2018 he got a urine infection, and his swallowing went funny on the Sunday. That was tough. The following day, his own GP came round and said we needed to send him to hospital and that was the weekend of the WG with the complaint. Justine is providing letters (exhibited with her statement) about this complaint and the standard of his care. A few things stand out about that weekend, leaving him with bedrails up and not getting him physiotherapy until the discharge meeting. On that day, they had our numbers but they didn't phone either of us to tell us that Dad needed more clothes and meant he had no clothes when I went there to visit him and get him ready for his doctor's appointment that afternoon. They were atrocious. At work I had someone admitted to the WG that week, and they had got a bed, so why did Dad not get a bed? That person

went in after Dad so something was wrong. They were too busy and we had to give Dad all the care. It was only at the weekend when it was quieter when we saw the staff could be caring. The rest of the time they were too stressed. He lay in bed for the week, like a caged animal. It was awful. The food was awful. He was discharged and went straight to bed because he was so tired. Then we got a phone call at 4:30pm from the hospital telling us that his urine had come back positive for an infection and they were going to send antibiotics. That was so frustrating. They didn't tell us until the end.

45. The speech and language thing with his swallow was ridiculous. This is also covered in the WG complaint in Justine's statement. At this point he was just getting frailer. I knew at this point, that the end was going to come sooner than we previously thought. In June I thought he would see my birthday in GRO-C but when he was in the WG the decline was so rapid, I knew the end would be sooner. Justine and I are of the opinion that that admission hastened his demise because he had a whole week with no antibiotics, so his immune system was getting into a state. He had no antibiotics, no proper food, no light, no proper care, no fresh air, nothing. It is a horrible environment, particularly for the older person. We haven't had a satisfactory response from the hospital either, as is covered in Justine's statement.

46. After those couple of days, he was so so, but between us and the double staffing, we were just about managing. Then on the Thursday he didn't have such a good day. This was the 12th July. He had a bad day, and that night I was on a back shift. Justine and Dad's night carer, Cameron were in the house. They texted me and said Dad wouldn't go to the toilet. It was so bad that eventually his bladder gave way. He couldn't get his trousers down fast enough and I couldn't help him because of the position he was sitting in. We brought the shower chair through and tried to persuade him to change. Eventually he did and we went through to the bathroom. Dad sat down on the toilet and then he wouldn't come off it. Eventually he had bent forward so far, that he had

GRO-C

had a dribble accident on his trousers. Historically, Dad would not tolerate any soiling of any kind, but on this occasion he stamped his feet and refused to move. Eventually I was able to help him change, but he would not get off the toilet. I eventually warned him that I was going to have to phone the night care team, to come and help. I phoned them and he didn't like this, but he still refused to move. It got to 00:30, but he wouldn't move. We even tried reverse psychology and went into the kitchen for a cup of tea, but he still wouldn't move.

47. Eventually the night team came round. He wouldn't move for them either. It was getting tougher and tougher and we had to phone NHS 24 and send for a doctor. The doctor wasn't going to come round for hours due to the time of night. Dad was experiencing a lot of anxiety. That kind of anxiety created a kind of fog for him where I couldn't figure out what was wrong. The anxiety was hiding it and there was all this subtext going on of what was really wrong. Eventually we worked out that he believed that if he fell asleep in his bed, that he was going to die that night. So I said if you come off the toilet we will let you go and lie on your recliner and we will stay with you, don't worry. Somehow we managed to get him onto the chair. Initially we got him to the living room and he was doubled up. He was too tired to move and if we let him sit on the recliner then, he would never be able to get into bed. Somehow we got him onto the bed, I can't remember how. It took 5 of us. Once we got him in and organised, we just stayed with him for hours. Justine went home eventually and I just stayed. I used my professional opinion that night and told him, "*You are not going to die tonight Dad*"

48. Eventually I get home and I tried to rest because I had another backshift that day at work. The following morning, poor Cameron, to his credit waited as long as he could I think to probably try and give me a rest, had to phone me to come round. He had had an atrocious morning with Dad, absolutely atrocious. I went over and the other home carer, who was also a retired nurse, was there. Between us we both knew what to do, so we got him sorted got him comfortable and I got him to take his

GRO-C

tablets. He was able to drink from a straw at this point. The doctor came that morning, as did the cancer nurse Lorraine, and it was good that they were both there. They quickly concluded that the disease was too advanced and that Dad was going to have to come into the hospice. Dad just accepted this. He had a bit of a nap, while we organised things and about lunch time the ambulance arrived. I phoned work and told them I couldn't come in. We ended up going a way that really meant something to Dad. We travelled through GRO-C where my parents used to live, down to Leith, all sorts of places that meant something to him and me. Dad couldn't see what was going on, but I could, so I described everything to him. I don't know how I didn't cry.

49. We got there and in my haste getting everything organised, although I had requested the holidays needed to take time off work and be with Dad. In my haste I had forgotten to request the previous weekend off. This meant that I had to work Saturday and Sunday. I was on early shifts both days so I did them and I went straight from work to the hospice. Dad was ok at this point so I knew he would still be with us on the Monday. The terrible thing was that one of the people I was looking after got very ill that day. Before Dad left the hospice the first time, they gave him palliative care medication just in case. I remember looking at it and I have to look at this stuff all the time at work. I was looking at this and it made me feel really sad. I was trying to prepare myself and after that day at work, I just sat still thinking about Dad. I went to hospice and he was still ok at that point. I knew what was going to happen though. Sometimes people are ok for a day or two when they are in a nice stable environment, they have sunshine and all of that. It gives them a chance to talk to people, get closure on things, set everything to rights.

50. I noticed that Dad, towards the end of that week around Thursday was developing a cough, particularly in the evening. Then on the Friday he was coughing more. At that point I didn't feel he was entirely ok. Not long after that he vomited. The staff came and sorted him, but by the time we went back in, he had a catheter and he had a continuous line

GRO-C

in. It was at that moment that my heart really sank. I didn't know when it was going to come, but I knew we were at the top of the hill and at some point we were going to be rolling down. I was pleased that the catheter procedure had gone well, because the problem with putting a catheter in an arm, is that you can get trauma. It is not necessarily anyone's fault that you get trauma, but the last thing you want with a haemophiliac male is trauma. That would have meant we would have to probably get more FEIBA.

51. After that he just went to sleep and then I got a call from my sister Storm first thing in the morning saying that he had vomited and got aspiration pneumonia. After that, he had to have something every half hour because he was gurgling and gurgling. Eventually the doctor came and got him sorted out and that was him finally settled. He had a very quiet day that day and he just slept and we played music to him. On the Sunday, he was still awake, but not talking. He was quite sedated. We were all there, sitting around the bed and I was sitting directly in front of him. He opened his eyes and looked at me quite piercingly and barked at me "*HAD ENOUGH*". He didn't say anything else after that.

52. He was breathing quite rapidly, and Justine moved round and reassured him that we wouldn't let him suffer. Then I said "*It is ok Dad I did hear you, I will speak to the nurse*". I spoke to the nurse and he got some more medicine from them. He had a terrible night though. He was gurgling and gurgling. There was so much fluid accumulating, it was horrible. They kept having to get stuff to dry it up. It was an awful night.

53. On the Monday it was a fresh week so the top consultants were in. They came round in the morning and they doubled Dad's dose and he had a better day. That night, Justine slept on the recliner chair in the room with him and I left her with him. They looked so cute. It reminded me of something that had happened to us as kids. We had been going down to visit Dad's parents in Suffolk and Justine was about 3 or something at the time. Dad got her wrapped up in a blanket and it made her look

GRO-C

really small. Dad carried her so she looked even smaller. It reminded me of that, they looked so peaceful sleeping side by side.

54. The following day they upped the dose a bit more. Everyone was there. It was a sunny day and his breathing was getting slower as the day went on. I put on a favourite song on at about quarter to ten at night which was Signifyin' Monkey by Oscar Brown Junior, certainly it was one of his favourites. Shortly after that Dad started to change a bit more, we were all gathered around him and he just went very quiet. At about quarter past ten I said to the others "*Don't press the emergency button, I'll go and get the nurse myself*". So all the others stayed with him. I had already told them, not in front of Dad but earlier, that even if you don't see Dad breathing, keep talking to him like he still there. He will be able to hear you for quite a while after he stops breathing and none of us wanted his last thoughts to be of annoyance. The first point in my working life that I knew that, I told them this. I didn't want them to start talking about something inappropriate. I explained to the nurse what was going on, and when I came back, that was definitely it, the nurse came round and at 22:20, Dad passed away. I knew what the nurse had to do after that because I have done it myself through work, then is a verification check. The last thing you want when you have to do a verification check is the family hanging around, you don't want spectators so, I ushered everyone out then for a cup of tea and then upon our return we started to pack things up.

55. Dad was offered the possibility of hepatitis C treatment in 2016. For various reasons, to do with how he was feeling at the time, he wanted to wait until his liver scan had been done, which was due in the early Autumn before treatment was organised. He knew there would be side effects so he wanted to make sure it was an appropriate time. I have no idea why the need for and benefits of treatment were not explained to him before 2016. I will probably never know. They had been checking his inhibitor and hepatitis C levels and his levels were always quite low, but I don't know how long the treatment was available to Dad. I think

GRO-C

56. He wasn't discriminated against for other procedures. He had some small minor surgeries as well as bigger surgeries throughout his life. In the early 2000s he had a transurethral resection of the prostate (TURP) and he broke his leg at the end of 2001. He broke his hip in the mid-2000s and he was never denied anything the doctors could give him. It was never an issue.

57. Mum and Dad had already split up by the time Dad was told about his infection. I don't think his third wife Patricia took it very well. She wasn't the easiest of people but I don't think she took it well. She was very upset GRO-C

58. Dad didn't bring Storm and Julia up. We had Dad all our lives, so there was a different relationship there. He loved his daughters though and he used to spend Christmas with Julia from about 2007 every year until 2013. After that, he was either in hospital or with us at my Mum's house down in the Borders. Everyone was there for Dad when they could be.

59. Dad never wanted anyone to know about the hepatitis C. There is a stigma with hepatitis as there is with other conditions like HIV. We found that it did help that most people did not know, but anyone in the care environment did have to know.

60. I have a degree in nutrition but I have always ended up going back to doing what I do now because given the current economic climate, I need to ensure I can support myself. I don't dislike my job, I do it with the appropriate amount of enthusiasm but I do find it is getting a bit tiring having been through the process of having to look after Dad. Everything that has happened has left me now wondering if I can keep up my role for much longer. My job title is Staff Nurse. At first, workwise I had to be incredibly open about what was going on. I could not keep anything to myself. I had to tell them everything. I realised that if I didn't tell them everything I was going to suffer some form of consequence

I had to be incredibly open about what was going on. I could not keep anything to myself. I had to tell them everything. I realised that if I didn't tell them everything I was going to suffer some form of consequence as I would be questioned about absences and following their own procedures. That helped a lot, my work was very good in the end. I worked out that I lost at least £12,000 in wages between 2016- 2018 from absences. I have never sought promotion, but if something more interesting had come up or another opportunity had come up, I wouldn't have been in a position to take it during those two years. I am at the stage of my working life now where I have done this for 34 years. By this summer I will have accrued maximum state pension contributions. I am worn out between the general strains of my job and Dad.

61. Those two years with Dad have aged me incredibly. I had arthritis in one hand previously but since those two years I now have arthritis in my other hand. I was incredibly ill before he died, I don't know how I kept going, it was pure adrenaline. In those two years, I developed hemiplegic migraines. I was vomiting with the migraines and they got really bad. I am not in the best of health anyway, bear in mind I've had supraventricular tachycardia when my pulse went up to 214 beats per minute, which is not nice. I've had a lot of stomach problems. In 2017 I had to have two endoscopies, one in May, one in July. I had to work and look after Dad simultaneously to all of this. I went and had the first endoscopy without sedation as I had to look after Dad as well, which was twice as horrible. They found I had severe ulceration and about 10 weeks later I had to have another endoscopy. For this one, I was going to have it with sedation as they told me I would have to be sedated.

62. The night before, Dad had had a reasonable day and he had gone through to the bathroom at midnight. At this point in July 2017 he was still doing a lot of his own personal care and he could not get off the toilet at all. Eventually around 4:30am or so, I said, "*Dad I'm going to have to clean you myself*" and he begged me not to. I said, "*I have to, I have to go for this endoscopy at 2pm. I need to go and have a rest. I*

GRO-C

have to". He then agreed. I finally got him into bed at 5am and got myself home for 5:30am, it was horrible. I've never been so glad to go away and have treatment. The instructions were that I wasn't going to be able to do anything responsible for at least 24-36 hours after the procedure so I was getting a complete break. Imagine an endoscopy being a holiday?! It impacted on my life in so many ways. I realised after the endoscopy it was probably more that Dad hadn't wanted to be alone rather than being worried about me.

Section 6. Treatment/Care/Support

63. There was an awful lot of victim blaming, making the sufferer feeling grateful for being treated. There was an awful lot of that. Do you know on the old Skipton Fund website, there was a section on criteria for funding. One of the things they said (it is not there now) was if you had been treated and cured, you couldn't get funding, you weren't entitled to get money. I think that is awful. It is like if a surgeon almost cuts your head off, sews it back on and your expected to be grateful. You are always going to be in some sort of pain from going through that. You are always going to be changed physically. You are never going to look right and you are expected to be grateful. He was also made to feel like a burden. So for example, it was always made clear to him how much his treatment cost. He always knew, he was always told this. That is not something a patient should know. They should never know that. They should just know that they are getting this treatment and they will be better. They should never be placed in a position of guilt.

64. Towards the end of his life, Dad was very frail. Despite the delays, the carers system in 2018 was largely organised but we still had to do periods of cover and so forth and when the carers weren't working it was Justine and me. By the end of June, we did have a full set of night cover in place which was helpful but a lot of the time we were having to double staff. Some carers had trouble with Dad on their own at the end,

GRO-C

for example there were continual troubles taking him to the bathroom. I was going to Dad's at that point, every day, even on my days off.

65. The home carers were very good, but the home organisation with the different carers, the Council and all the change, that was hard. Really hard.

66. When Dad had to be admitted to the Royal Edinburgh after his second suicide attempt, we spoke to him and warned him that there was no choice, that he needed to detox etc. He didn't want to go in though, he was in a terrible state. Everything about the hospital in Justine's statement is true. It was an awful place. Interestingly, I could see that if the staff weren't off sick and things were being managed, that it could be ok. I could see that if the anti ligatures weren't there and the fact you couldn't lock a door wasn't there, it would have probably made an alright hotel, except for the acoustics...they were awful! There was something wrong with them. On one hand you want to hear your patients no matter where you are, but on the other hand it was awful. It was so noisy. The staff were so busy as well. I wish we had already managed to get St Columba's on board at that point and not the Marie Curie people. I wish it had been different and he could have gone there as that environment can be as secure as anywhere and Newhaven is in the middle of nowhere. They were the only place that was decently staffed and 98% of the time, they did everything perfect. He would have been happier and possibly not continued on into the horrible decline.

67. Palliative care is stretched and there aren't enough resources to support people. What would have happened if Justine and I were not available? All the resources are very stretched. It is not the fault of the individual Health Board, a lot of this is down to the austerity situation. It isn't good enough though and is morally reprehensible. People are just left to struggle. There should be the same level of support at the end of life as there is at the start.

GRO-C

Section 7. Financial Assistance

68. In the spring/summer of 2004, I was looking through a newspaper and I saw an advert for the Skipton Fund. I phoned Dad and gave him the number. I told him about it and he successfully applied. No one ever approached him, it was pure chance that we saw it.

69. Originally, Dad received £20,000 in 2004. In 2017, he received £40,000 and £3,000 every three months after this. Dad used to bitterly go on about the compensation amounts. He found out that if he had lived in Ireland, he would have received a much larger amount and more support. He always felt angry that he didn't get the same. He could not believe that the British Government were treating people worse than they were in Ireland. He used to talk about finding a way to go to Ireland and live in a caravan for a while, put on a thick accent and appear at a Haemophilia Centre in Ireland. It makes me laugh thinking about the idea, but on a serious note, yes they should all be treated the same.

70. The process of applying was a case of filling in a form and then he had to go see someone at the Haemophilia Centre to confirm his diagnosis etc. The second time, Justine completed the forms and got the oncologist to complete the forms. The process wasn't as easy as it could have been. You had to get all this information together from all these people and there were cut off dates as well. Our understanding was that if he didn't apply by the end of January he would have to wait until April to reapply in 2017.

71. No amount of money can ever compensate you ever for something like this. The most you can hope for is that your life is more comfortable. Regardless of your infection status, the compensation for everybody should be a lot higher than it is. If people develop cancer they should get every available assistance and automatically get every sickness benefit they can, just everything. He should have been offered proper advice about treatment in the first place and they should do more for

GRO-C

the families. They don't do enough for the families. Everything seems to revolve around a single infected person on their own or a married couple. There is no provision whatsoever for divorced people, children, separated people, no provision, which is ridiculous. Think about it, most haemophiliacs/people who were put in that situation, a large number of them have probably ended up being divorced and in many cases there may be children. The children are left to do everything and we get nothing. You don't think about yourself when you are caring for your parent, you are focused on them. But why should we be left worse off because we are the children as opposed to the wife? Washing the dishes, making the meals, caring for their personal care we did all of this for Dad right until the end. By the time someone like Dad is that ill, the person with them, is simply their carer. The parameters change. Emotionally it is different but on paper it is the same. It isn't fair that we are treated differently in that respect. We have suffered just as much.

Section 8. Other Issues

72. Thompsons Solicitors are recovering Dad's hospital records which I will be given the opportunity to review once available and if there are aspects of this I wish to provide to the Inquiry once they are available I will do so either myself or through my sister Justine Gordon-Smith.

73. I find it reprehensible that there is such a lack of support. There aren't automatic processes put in place for support and care when it is so vital. I cannot change what has happened, but I wish it hadn't happened. If it could have been avoided, if what happened to Dad could have been avoided, that will be the most inhuman thing ever.

Statement of Truth

I believe that the facts stated in this witness statement are true.

GRO-C