

A19G0201

Witness Name: James Anderson

Statement No.: WITN3097001

Exhibits: None

Dated: 26<sup>th</sup> August 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF JAMES ANDERSON

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 27<sup>th</sup> June 2019.

I, James Anderson, will say as follows: -

#### Section 1. Introduction

1. My name is James Anderson. My date of birth is the GRO-C 1947. My address is known to the Inquiry. I am happily married to Dorothy Anderson whose date of birth is the GRO-C 1945 and I am a retired Governor. We have two adult daughters and five grandchildren. I worked in the prison service for over thirty years and then after I retired in 2002, I volunteered for ten years on the Children's Panel. I am presently the chair for the British legion in GRO-C I intend to speak about Dorothy's infection with hepatitis C which she contracted when she received a blood transfusion in July 1979. In particular, the nature of her illness, how the illness affected her, the treatment she received and the impact it had on her and me and our lives together as a family.

2. I have appointed Thompsons solicitors to represent me for this matter. I do not wish to be anonymous for this statement.

## **Section 2. How Affected**

3. Dorothy and I met in 1972 and got married in 1973. We moved around over the years because of my job in the prison service. In 1979 we were living in [GRO-C], Dorothy developed a kidney stone which left her in severe and continual pain. She was admitted to Stirling Royal Infirmary with the intention that the kidney stone would be removed. It was a routine procedure and not done on an emergency basis. On the day of the operation, the doctors advised Dorothy that she was too anaemic for it to go ahead. In order to make her fit for the procedure they advised her that she would require a blood transfusion. This took place in July 1979. She accordingly received the transfusion that day and had the kidney stone removed the following day. Her recovery took sometime after the procedure, because in those days it involved a complicated operation to remove a kidney stone, she carries the scars from this, to this day. This is how we believe she was infected. She has told me that she received two units of blood.
4. No doctor spoke about the risks that Dorothy faced by receiving a blood transfusion to either her or I. She was not given the choice, despite the fact it was not life threatening; it was a case of this was going to happen and that was the way it was.
5. Over the years after this, Dorothy has mainly been in good health, except for excessive, unexplained tiredness. She has also had other operations, including a hysterectomy in 1993. Never once, was hepatitis ever raised when she had these procedures until the point when Dorothy went to her GP because she was constantly feeling extremely tired.
6. Dorothy went to her GP, Dr [GRO-C] at [GRO-C] around 2002/2003 because she was feeling tired and listless. They arranged for

a blood test and then all of a sudden she received a letter through the post saying further to our tests, you have hepatitis C. There was no explanation, no information, nothing. She was poorly treated and she didn't know what to do. Of course with me being in the prison service, I knew of a lot of people getting treatment for hepatitis C which left me questioning where had this come from, had I brought this home with me? I went for a test through my own GP, I was clear of the infection so we were left with the question of where do we go from here. Dorothy went to see Dr GRO-C upon receiving this letter who said he would contact the hospital about the results. She was referred on to Dr Bhattacharyya a specialist in the Infectious Diseases Department, which is a horrible label to be tagged with. After the referral, no one from her GP surgery ever contacted Dorothy again in relation to this. They must have received letters from the hospital, especially when she was undergoing the hepatitis C treatment, but once she was at Victoria Hospital, Kirkcaldy that was the end of all involvement with her GP.

7. Dorothy has been anaemic most of her life, to the point she received iron injections for a long time because her haemoglobin levels were too low, so when the proposal of a blood transfusion was given to her in 1979 she wasn't surprised. After her diagnosis, she questioned the hospital why the hepatitis C had never been picked up on before. Indeed, Dorothy had a few procedures, including a hysterectomy on the 19<sup>th</sup> February 1993, so it was puzzling that this had not been picked on earlier as a test was available at this point. The response was that the doctors had never tested for hepatitis C until 2002/2003. We found out through speaking to people at the Edinburgh hearings in July 2019, that this was simply not true, a lot of people found out a lot sooner than Dorothy.
8. I was home when Dorothy received this letter. She was devastated, bewildered and angry finding out she was infected and by receiving this information through the post. There was no invitation to come into the surgery to discuss it, the way it was handled by her GP was extremely poor. She thought it was someone else's letter, that it was a mistake;

she simply didn't know what to do. I think Dorothy received the letter a couple of weeks after the test was done and then she had to wait about three or four weeks after that to be seen by Victoria Hospital, Kirkcaldy.

9. In that six weeks waiting to be seen, it was an incredibly worrying time. We were left questioning how it had occurred and had it been my fault through my work. She made the decision that she didn't want any of the family to know at that point as she didn't want to worry them. At this point we only had one grandchild and she was even afraid to give him a cuddle or a kiss in case he would catch the disease. She decided to keep it quiet until we got more information.
10. The day Dorothy went to see Dr Bhattacharyya, that was the first thing she asked him, would she be able to cuddle her grandson. She was scared that by even kissing him on the cheek, that the fluid from her lips could infect him. She just didn't know what she could or could not do with other people. Dr Bhattacharyya advised her that she would have to have a cut and our grandchild would have to have a cut and the two bloods would have to mix.
11. While this was reassuring to a point, she still felt like a leper. The hospital were reassuring her but it almost didn't matter because in her head, her imagination was looking at all the possibilities. The hospital were saying no it was fine but obviously it wasn't, so how could she trust this new information? She put her life in the hands of the medical profession and trusted them, it has given her an incredible knock this diagnosis because they knew about the blood and they still chose not to advise her. She was also determined not tell any of her friends and she ended up having a change in lifestyle and although she only took alcohol on social occasions, she stopped completely.
12. Dr Bhattacharyya told her that she had the worst strain of hepatitis C and if she was to have treatment it would be a long treatment with low odds of success. At that time the course of treatment was nine months long. Dorothy weighed up the odds and decided not to go for treatment at that

point. Up until then, nothing had really occurred to her physically that we were aware of, apart from her feeling tired. She was busy because at that time we had more grandchildren and she was doing a lot of child minding before they went to school, she didn't want to cause a disruption by stopping this. She wasn't on any medication, she was just going to hospital for annual check-ups from then on. She buried the information as deep as she could in her mind and only thought about it when she returned to the hospital. It was only when she went back every year, that she had to face it and this would be the point when she would get really upset. Psychologically she stopped herself from dealing with anything and she would end up having a breakdown when she went back to the hospital.

13. She felt like she was considered to be on the same level as a drug addict. Indeed she was sitting among drug addicts waiting to be called when she attended. On occasions when I went along to the appointments with her, I was always worried that there would be prisoners or ex-prisoners there which would have had its own implications. It was horrible for Dorothy feeling that she had this disease in her body through no fault of her own.
14. e weren't given practical information to understand the infection to be honest. The doctors were poor at communicating with us. We also thought that Dr Bhattacharyya's was a poor communicator which made these visits difficult. The nurses were a lot of support but not the specialists overall. Information should have been provided as soon as she had the test.
15. Nothing was straightforward, nothing was clear, we felt kept in the dark about what was going on and what had happened and what her long-term prognosis would be. I went to my own GP surgery and spoke with a nurse about the circumstances and requested a test for myself. I saw a nurse, no doctor ever spoke with me. There was a big red sticker on my test with HEP C printed on it which I found uncomfortable. I had to

follow-up for the results, no one contacted me. I was told I was clear, but I think a doctor could have had a word, but no, there was nothing.

### **Section 3. Other Infections**

16. I am not aware of Dorothy having ever contracted any other infections other than the hepatitis C from receiving the blood transfusion.

### **Section 4. Consent**

17. Dorothy didn't know what they were testing her for, let alone it being hepatitis C, so there was no communication about what they thought it could be until the infection came to light. It could have been that they were testing for everything and that is why it was discovered.

18. Dorothy's medical records have disappeared. None of her records are in existence after September 1979. If you look at the records that are in existence, there are references to her having low haemoglobin levels and a reference to having an iron deficiency, there are all sorts of references around this when she was admitted to hospital for the run-up to the operation in 1979. There is information about low haemoglobin levels and all the rest, except no mention that she received a blood transfusion.

19. I have no knowledge about if she has ever been used for the purposes of research.

### **Section 5. Impact**

20. The diagnosis itself has been life changing. There are a lot of mental things that have gone on for her that I can see still impacts her to this day. I have to watch what I say to her as I could inadvertently upset her without meaning to. I think she has been mentally affected worse than physically from what I can see. The illness is never far away, however I see the mental side, I don't see the physical side. Anything that goes

wrong for her, there is always a fear or a connection made that it could be hepatitis C. If it ever appears on TV it brings it all back to her as well. The fact that her medical records are missing, I believe is criminal.

21. Dorothy has developed depression over this but she has not gone down the road of speaking with her GP for support because she feels that they would put her on medication and she does not feel that this is appropriate. If it wasn't for her hepatitis C nurse, Karen Thomson, there would be no other emotional medical support.
22. When she went in for a biopsy she wasn't allowed out of the ward. They asked her to come in the day before, so she went in the afternoon to the infectious disease ward. I came to the door and the nurse said to me sorry you can't come in, which was because of the nature of the ward. I said bye to her and she showed Dorothy where she was staying. In her room there was a white line across the floor and the nurse warned her not to cross the white line under any circumstances. This was fine, because most of the facilities were inside her room so she didn't have to go anywhere.
23. The next morning a nurse came in and she asked if she could have a shower. This nurse said yes, it is down this corridor. Dorothy said to this nurse she was not allowed over the door and the nurse said well you will have to because the shower is down here. She went down the corridor and saw that someone had just finished using it. Dorothy commented to the nurse about this and the nurse agreed saying yes, but it is the only shower. Dorothy challenged her then saying *"so I am not allowed to come out of my door, at all unless someone takes me for a biopsy, yet I have walked right through this ward, I don't know what other diseases these people have got and I am to shower in a shower room that has just been used by someone else...with an infectious disease"*. The nurse agreed saying it wasn't right but it was the way it was.

24. Dorothy did eventually have the shower but considered it for a long time, and ended up rinsing the shower quite thoroughly as there was no cleaning products, so she couldn't even give it a clean. It left her thinking, what was the point in that? The nurse didn't even bother to see if she went straight back to her room or if she went into another room.
25. Dorothy was monitored for years, attending hospital once a year. Eventually she was offered this treatment but she was advised that there was a low incidence of success. She was warned that she would be bedridden, because the treatment was so difficult, so with that information she declined. It was only when they came up with a new type of treatment, with a higher success rate did Dorothy decide to go for it. That was when she told our family and friends that she had been infected. She finally went through the treatment which was ultimately a success.
26. From being diagnosed in 2002 to finally getting the treatment in 2014, it left Dorothy with 12 years of isolation. She was never warned about the state of her liver in all these years, she would have tests done every time she attended the hospital for a yearly appointment, but she would have to ask for the results of these tests the following year when she went back for her next check-up appointment. The first treatment was never really encouraged and we think this was because of the low incidence of success. Dorothy did keep asking about other possible treatments for a very long time but she was always told there was nothing else.
27. When Dorothy did undergo treatment for the hepatitis C, she took tablets daily and received one injection a week. It was a huge pre prepared needle. Her hair was falling out which got her down quite a lot. She has been left with the side effects to this day including having brittle nails. It was when Dorothy read about a new treatment for hepatitis C with a better success rate and lesser side-effects she broached the subject with the hospital. She raised it with Karen and asked to be considered, Karen



spoke to the consultant that took over from Dr Bhattacharyya who had left the hospital at this point and they gave permission for it to go ahead.

28. It was a funny one because it was a consultant that Dorothy only ever saw once, during an initial consultation after Dr Bhattacharyya left. The whole time she underwent treatment, all her contact was with Karen who took over the case and another nurse assisted called Grace. Karen did everything for her in relation to the treatment that was needed. Even when Dorothy was finished, the consultant never called her back to speak to her about what had occurred and the results.
29. Dorothy was very scared when she started treatment, and taking the injections was always difficult. She managed to get through that and the further she got through the treatment, hope began to emerge. Karen was doing something practical to help Dorothy and that allowed for light at the end of the tunnel to come through. The moment when Karen told us that the virus was considered non-detectable partway through her treatment, it was a relief and that remained the case for the remainder of the treatment. Dorothy was down a lot though, everything became an effort. Mentally it has left its mark.
30. Dorothy has been through a gruelling treatment for the hepatitis C but the doctors won't say to her that she is cured, they will only say that her virus is non-detectable. She met someone at the Edinburgh hearings who asked for a test and was given this test straight away by their treating hospital. This person was told that they could go any time for a test and it was not an issue. As a result, Dorothy then phoned up Karen and asked her for a test and Karen was very amenable, it was all arranged. Karen then phoned Dorothy and told her the results, it was good news, the virus was non-detectable. It is interesting that they will still not say 'you are cured'. It always leaves her with the possibility that it could come back.

31. Her infected status didn't impact upon treatment for any other conditions that I can recall.
32. When Dorothy did tell the children, they were very supportive and thought that she was very brave to have held it together for all this time. She has some very good friends as well who have been supportive of this very brave lady. During the whole thing, she couldn't take part in drinking alcohol or any social activities, her friends must have wondered why she had suddenly stopped but it would have not been a big deal because she is only an occasional drinker.
33. Emotionally I always had to be careful not to mention the word hepatitis C when around family and friends. I had to be on guard, but other than that no it didn't affect me, other than to be worried about Dorothy.
34. I retired from work in 2002, so there was no work-related impact for me and Dorothy was not working.
35. There has been no real financial impact from the hepatitis C. She had to inform her travel insurer about her infection but now she doesn't tell them because she is supposedly cured. When she did declare it, her rates increased dramatically. It also has left her with the question if she is being truthful or not, because the hospital don't use the word cured, only 'non-detectable' so where does that leave her?

#### **Section 6. Treatment/Care/Support**

36. When she was going through the treatment I took over a lot of the household tasks. We share chores and household tasks normally, but I just did anything that needed done while she was unwell.
37. Karen and Grace did offer Dorothy psychological support at some point, she declined it because she has a fear of being put on medication. Psychological support would not have helped me.

## **Section 7. Financial Assistance**

38. Dorothy found out that financial help was available from Karen Thomson her hepatitis C nurse.
39. Dorothy applied to the Skipton fund and was rejected on the basis that there was no evidence that she had ever received a blood transfusion. Again because Stirling Royal Infirmary have no record of this. Dorothy and I have never heard of the Scottish Infected Blood Support Scheme (SIBSS).
40. Dorothy was infected with hepatitis C through this blood transfusion and on that basis, she is entitled to some monetary compensation, but first of all she wants the evidence to prove it. For the profession to destroy her records and not accurately record the information, it is unacceptable.

## **Section 8. Other Issues**

41. I stood in a queue with prisoners to donate blood when I was working. That was in Aberdeen prison in the early 1970s. Prisoners got time off work, a cup of tea and biscuits to give blood, it wasn't compulsory. It was an escape for them, something different to do. They weren't paid for it. In the 1970s drugs were just starting to come into prisons.
42. This entire area, feels very secret, she has to fight for anything to find out information. The GPs never discuss it, the hospitals are vague, it is an unspoken subject that is not discussed. Thank goodness for Karen Matthews, she has been a godsend support for Dorothy.

A1950201

**Statement of Truth**

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

Signed

GRO-C

Dated

5-3-2020.