

Witness Name: Janice Adams

Statement No.: WITN3274001

Exhibits: **WITN3274002**

Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF JANICE ADAMS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 28 May 2019.

I, Janice Adams, will say as follows: -

Section 1. Introduction

1. My name is Janice Adams. My date of birth is GRO-C1951 and my address is known to the Inquiry. I am a sales assistant in a local shop where I have worked part time for the past 24 years. I have two children and three grandchildren, with a fourth expected soon. I intend to speak about my mum's infection with Hepatitis C ('HCV') and in particular, the nature of her illness, how the illness affected her, and the impact it had on her and our lives together.

Profile of my late mum

2. My mother Doris Emily Maud Retter was born on **GRO-C** 1919. She was a teaching assistant for 30 years until she retired. For the majority of her life she lived in London and then moved closer to me when she got older.
3. Around 1982/1983, my mum underwent a hip replacement operation in the Whittington Hospital, Archway, North London. As a consequence of complications during this operation she received a blood transfusion.
4. Sadly, my mother died on 3 April 2005, her death certificate stated Bronchopneumonia and Cirrhosis of the Liver as the causes of her death **WITN3274002**. My mum was not a heavy drinker, drinking only on special occasions, such as a sherry at Christmas. She also did not have any tattoos therefore; I can only conclude that Cirrhosis of the Liver was caused by Hepatitis C, contracted from the blood transfusion she had in the early 1980's.
5. I am not legally represented. The investigator has explained the anonymity process to me. I do not require anonymity, as I have nothing to hide. The infected blood scandal should not have happened but I want my mum's story out there to help to prevent anything like this happening again.
6. I do not criticise any medical professionals in this statement but the investigator has explained the 'Right to Reply' procedure to me.

7. I was referred to the Infected Blood Inquiry by the Hepatitis C Trust.
8. It has been a while since this all happened to my mum; I have tried to recall the dates however, dates provided should be treated as a rough approximation and not as definitive as my memory has faded over the years.

Section 2. How Affected

9. Prior to 1982/1983 my mother had no medical history or events in her life that could have lead to Hepatitis C. The only blood transfusion she ever received was as a consequence of the hip replacement operation and she was never treated with any blood products.
10. She had a brief, but serious episode of Thrombosis of the leg. This is the only significant medical problem my mum experience before the accident, which ultimately lead to her needing a blood transfusion.
11. In the summer of 1981, my mother was visiting me from London at my home in GRO-C Essex, when she broke her leg. She fell over in the shopping centre in Chelmsford on a slippery surface after it had been raining. Following the accident, she was taken to the Chelmsford and Essex hospital. She went into A & E where X-rays were taken, revealing that she had broken her fibula and tibia. This resulted in her being in plaster from her ankle to her hip. After two weeks or so she returned

home to London. She remained in plaster from around 5/6 weeks; her care was transferred to the Whittington Hospital, North London.

12. After around 6 weeks, in September 1981, my mum attended an appointment at the Whittington Hospital to get the plaster cast removed. As we stood up to leave the consultation room, the doctor noticed that my mum was limping. When questioned by the doctor, my mum said she had arthritis, which she supposed was causing her limp. The doctor then sent her for an X-ray immediately.
13. When the results came back the Dr confirmed that she had severe arthritis. He then proceeded to ask if she had ever considered a hip replacement. The doctor said that he would recommend his own mother to under go the procedure. I asked the doctor questions including how long the waiting list was, the doctor confirmed it was around 9 months.
14. After considering the procedure, my mum decided to go ahead with the hip replacement and had the operation in around May/June 1982. She went into hospital for the operation in the morning; my dad and I accompanied her to the hospital. We were told to return at 5pm when it was expected that the operation would be complete.
15. When we arrived at 5pm my mum was still not out of surgery. I asked a nurse where my mother was, she told me that there had been a *'Little bit*

of a problem in the operating theatre and she has had to have a blood transfusion, she's in recovery and will be back with us soon'.

16. My mother came back to the ward at around 7pm she was very pale and was sick. She was groggy and was still clearly affected by the anaesthetic. She hadn't come round properly and did not do so until the following day. We were told nothing more about the blood transfusion after that. There was no information regarding why she was given the transfusion.
17. I accepted that the medical staff knew what they were doing and that the transfusion had been necessary. I trusted the judgement of the medical professionals. I did not question the transfusion, as I was just so happy that she was alive after complications during surgery. My Mum put all professionals such as doctors and solicitors up on a pedestal and did not want to question their judgement.
18. She was in hospital for around 2 weeks, as soon as she could climb stairs she was allowed to go home. The mechanical element of the operation was a success. After the operation her hip did not cause her any further pain. As far as I am aware the GP did not contact her after the operation. I am unaware of any out patients' appointments at the hospital.
19. I would have known about any follow up appointments because I always travelled from Chelmsford to London to ensure that my parents attended

all of their medical appointments. Therefore, I can only conclude that no outpatient appointments were made. I would always be the one to call and make appointments for my parents at the GP and the one to take them for their appointments. In this period of time I cannot recall any appointments.

20. In the summer of 1990 my parents moved from London to live near me in

GRO-C

My mum was in good health at that point. Her health only started to deteriorate after my father passed away in January 1997.

21. In around summer 2000 my mum's health started to deteriorate further.

My mother used to go to stay at my brother's house at the weekends whilst I was working. She had had a couple of funny turns, feeling faint or sick. At this point in time, she was very weak and tired. She also experienced quite dramatic weight loss; she was always a bigger lady but she went from around 14 stones to around 8 stones. She lost her appetite and did not drink fluids. She did not want to drink, as she would then have to get up to go to the toilet; I had to tell her to drink.

22. Prior to this period, when she lived in London, she had experienced 'Black-outs' and fainting episodes. These events seemed common from around the year 2000 onwards. She also experienced pains in her legs and she had a little bit of memory loss.

23. In the summer of 2001 my mum told me that her skin was itching. She showed me a rash, which had developed; it was all over her back. The skin was scaly, red and inflamed. I thought it was Psoriasis; I booked her an appointment at the GP. The doctor prescribed different creams and none of them worked, she would scratch at her skin until it bled. We went back three or four times to the GP. As a consequence, the GP then ordered blood tests. The doctors did not disclose the blood tests results to my mum.
24. Towards the end of 2001, the regime changed in terms of blood tests. Tests were now being performed on my mum around every 3 months. I was concerned as to why she was having these tests.
25. In 2002 I decided to find out what was going on, at the next scheduled blood test appointment, I asked why my mother was having these tests. I asked her GP *'Why are you testing my mum's blood so much?, or don't I want to know?'* He said, *'He was testing her white and red blood cells, that was all he was doing'*. I assumed that these tests were to identify the cause of the rash. No other explanation was offered to us.
26. In around January/February 2003 I took my mum to Broomfield Hospital A&E as she had had a fall at home. Her carers discovered that she had collapsed behind the front door. I took her to A&E where they performed more tests, they failed to find anything wrong so they discharged mum at

2 am and I took her home. At this time there was no mention of referral to GP.

27. From this point onwards there was a history of fainting episodes, on around 6/7 different occasions. The GP said nothing about this. One weekend she took a turn for the worse, she was hallucinating, and saying things such as her dead son was on top of the wardrobe. At this point we called out a Locum doctor for a house visit. He examined my mum in front of my brother and I.
28. The locum asked how long my mum had had a large stomach for, her stomach appeared as if she was pregnant. I told the doctor that her stomach had recently begun to get larger. He produced a post-it note out and wrote something on it. He told me to give this to the GP; he told me that he thought that my mum had cancer. The doctor put the hallucinations down to my mother being dehydrated.
29. Following this episode my mum was admitted to hospital, she was still itching constantly. She would scratch her skin on the mattress of the hospital bed. The medical staff mistook this for her writhing in pain and wrote her a prescription for morphine; I did not think that was correct. After a day or so in hospital the doctor said they had a few more tests to do and then they would talk to us.

30. The doctor finally called us in and said that my mother had Cirrhosis of the liver. I said that this was not possible as Cirrhosis was something that drinkers got and I knew that my mother was not a drinker. The doctor asked had she ever had Hepatitis C. I said, *'No, the only thing she ever had was a hip replacement 30 years ago and that as a consequence she had to have a blood transfusion'*. The doctor said sheepishly *'Oh'* and did not elaborate. At the time I questioned this reaction. I think that the doctor knew that the blood transfusion 30 years before had been contaminated, and that this was the link to the Hepatitis C. Hence on my mothers death certificate it states 'Cirrhosis of the Liver' as a cause of her death **WITN3724002.**

31. After my mum passed away a consultant asked to see me in private. He said that he knew that I was not happy with the death certificate. He asked would I like him to change it? I was not happy because in my mind Cirrhosis implied that my mother was a drinker, which my mother was not. I don't know what he would have changed it to. I asked if changing the certificate was going to bring my mother back, to which he replied, *'No'*. I decided, therefore to leave the death certificate as it was.

32. I believe that my mother's death was caused by the blood transfusion with contaminated blood at the Whittington Hospital in 1982. I believe that is the causal link to Hepatitis C, which I believe she had, but was not formally diagnosed with.

33. Medical professionals provided me with no information, all that happened was a few days before she died the doctor at the hospital told me that she had Cirrhosis of the Liver. This information came far too late; the link between Cirrhosis and Hepatitis C was only made around 2 days before my mum died.
34. I believe more information should have been provided with the blood transfusion, we were not made aware of any risks. We still do not know why she needed the transfusion. To be told two days before she died is unacceptable.
35. There was no communication between my family and the medical professionals that was the problem. In hindsight it is not beyond the realm of good practice to tell the patient and family what exactly the medical problem is.
36. Due to the fact that my mum remained undiagnosed for so long, we were not given any information. I can't understand why the medical profession were so secretive about what was happened to my mum.

Section 3. Other Infections

37. I do not believe that my mother contracted any other infections other than Hepatitis C from the blood transfusion.

Section 4. Consent

38. My mother frequently had blood tests; none of the family were given an explanation as to what these were for. In my opinion she was certainly tested with out her knowledge, as doctors never explained to us what they were testing for.
39. On the subject of consent, I do not believe my mother was ever asked if she consented to these tests. I believe that she never objected because she believed that doctors knew best.
40. I believe doctors were aware of what was wrong with my mum because they did so many tests, the results of which must have allowed them to draw conclusions. They never passed this information on to us.
41. I am not aware that my mum was treated or tested for the purposes of research.

Section 5. Impact

42. During the last 18 months of her life, the intense itching of her skin caused her immense distress; we all assumed it was psoriasis. Only when she was in her last days did the truth emerge about Hepatitis C and now we know the real truth and why she experienced the itching.

43. The intense itchiness of her skin caused her quality of her life to decrease significantly. She frequently fainted and was fatigued; she was unable to walk very far. Due to her symptoms she lost a lot of confidence and felt unable to go out by herself in case she felt unwell whilst out alone.
44. My mother had no treatment and none was offered, as we were only told 2 days before she died that she had the illness. Had my mum been diagnosed earlier, treatment could have been offered or received. My mother faced no obstacle because no treatment was offered due to the circumstances under which she was diagnosed.
45. There was a total lack of information and treatment. I think that this is unacceptable, I am angry as I believe that a wrong has been committed that needs to be put right. By that I mean doctors should have been honest with us. I think about how the lack of early diagnosis impacted negatively on my mum's every day life. I wonder if she had been offered treatment to clear Hepatitis C if her quality of life would have been improved?
46. Having Hepatitis C although she did not know about the diagnosis, greatly impacted my mum. She enjoyed a family get together but she would often display symptoms especially fainting and complaining about feeling itchy. This would take the shine off the events. She could not go out and socialise, I had to take her everywhere. She was frightened to go out on her own because of safety reasons and feeling faint. Remarkably

although unwell herself, my mum cared for my dad who had Parkinson's disease. She did this until his death in 1997.

47. My mum's illness also had a significant impact on me. I had to attend a lot of hospital and doctors appointments, this is why it suited me to work in the evening. I had to adapt my career choices to accommodate my parent's medical needs.
48. My mum's condition affected my brother Gordon, as he cared for my mum too, especially at the weekends when I was at work.
49. My mum definitely missed out on life with her grandchildren due to her illness. She was not well enough to care for her grandchildren.
50. My mother would have been mortified to see that her death certificate states 'Cirrhosis of the Liver' as she would have associated this with people who drank alcohol to excess. My mother was not a big drinker at all, only drinking on special occasions. My brother was also very shocked at this diagnosis, as he knew that our mum only drank very occasionally. I think Hepatitis C has a huge stigma attached to it, one that my mum definitely would have recognised.
51. I had to diversify my working pattern, choosing to do shifts in the evening to accommodate my mother's medical appointments. This made it easier for me to transport them to and from the hospital.

52. I am unable to put a figure on the financial impact my mothers illness had on me. However, this figure should take into account the money spent on providing transport to the local hospital which was a 30 mile round trip. It should also include parking charges and time taken off work to take her to appointments; all of these factors added up over the years. I feel that these are costs that should not be overlooked.

Section 6. Treatment/Care/Support

53. Throughout her life after the transfusion my mother was never aware that she was infected with Hepatitis C, so this did not affect her access to medical treatment.
54. I have never been offered any counselling or psychological support. However I do not think I would benefit from this. I also believe that my mother would not have benefitted from counselling either, as she was never one for joining groups. Today the Inquiry investigators have made me aware of the British Red Cross support line and the services that I can contact to support me after giving my statement. I will give some thought as to whether this is appropriate for me.

Section 7. Financial Assistance

55. We did not apply for any financial assistance packages as we did not know my mother was infected with Hepatitis C until her death. Therefore we were not aware of the application process or what packages were available to her. It is only when the investigator has explained the process around securing payments from the EIBSS that I have become aware of assistance available. I would say that this was never about money; it was the need to know what happened and why it was covered up.

Section 8. Other Issues

56. I want the people responsible for the infected blood scandal to be honest and open and not to cover things up as, at a later stage this will come back to haunt them in the end.
57. This scandal has caused lots of people financial difficulty and as such it has affected their whole family. It is like a ripple effect; if someone that is reliant on a family member financially, when that person dies unexpectedly the family is then left in limbo to cope with a situation they never thought would happen.
58. I would like to see justice for all those infected and affected, I want someone to accept responsibility; I would like to find out who made these

decisions and who is accountable. I want to know what is going to be done in the future to prevent this from happening again.

Statement of Truth

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

Signed GRO-C

Dated 11/06/2019