

Witness Name: William Michael Hayes

Statement No.: WITN3618001

Exhibits: WITN3618002

Dated: 25 September 2019

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF WILLIAM MICHAEL HAYES

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 12 August 2019.

I, William Michael Hayes, will say as follows: -

#### **Section 1. Introduction**

1. My name is William Michael Hayes. My date of birth is GRO-C **1949** and my address is known to the Inquiry. I used to be a full-time carer, but I retired early due to ill health. I suffer from Chronic obstructive pulmonary disease ("COPD"), diabetes, asthma and angina.
2. I intend to speak about my mother, Miriam May Hayes, born GRO-C **1918**, and her infection with the Hepatitis C Virus ("HCV"), which I believe she contracted as a result of being given contaminated blood via transfusion. She died on 5 February 1977. I have provided her death certificate to the Inquiry (**Exhibit WITN3618002**), dated 7 February 1977, which states that the causes of death were liver failure, 'chronic active hepatitis', and 'infective hepatitis'.

3. In particular, I intend to discuss the nature of her illness, how the illness affected her, the treatment received and the impact it had on her life and the life of our family.
4. However, I suffered a series of infarctions a couple of years ago, which damaged my brain and has affected my memory recall ability. This, coupled with the emotion of talking about these very painful memories and the passage of time over forty years, mean that it is difficult for me to remember what exactly happened. As such, the chronology of events and dates that I will discuss in my statement, should be used as an approximative and not a definitive timeline.
5. I should declare that there are a lot of gaps in my knowledge of my mother's medical history. All medical information in relation to her was provided to my father, who chose not to share it with me, in order to protect me. In addition, I do not have any of my mother's medical files, and it is my belief that they are not in existence today, as they date back to the 1960's and 1970's.
6. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement. My carer and advocate Debi will assist me with documentation and reading of my statement when it is complete.
7. The investigator explained to me what the 'Right to reply' process is, should I make any such criticisms of individuals or organisations. I am aware that there is an existing agreed procedure that will be followed in such an event.
8. The investigator also explained to me the anonymity process, and I have chosen to proceed with my identity being made public. I provide this statement to the Inquiry, because I want the story of my family to be heard.

## **Section 2. How Affected**

9. My mother had always been very healthy. She was gorgeous, bright and bubbly. She enjoyed cycling and would cycle to work everyday. She used to work at Woolworths store in Canton, Cardiff and looked after me and my brother and sister. I was her youngest child and was very attached to her.
10. I confirm that my mother did not have any tattoos or piercings. She only wore clip-on earrings. She never drank alcohol and never took drugs, except the ones prescribed by her GP.
11. Unfortunately, my mother developed shingles on her face in 1965 (I was 16 years old). This terrible illness was diagnosed by her GP at the time, Dr Gulliford, in Cardiff. The shingles looked like fish scales. They severely scarred the left hand side of her face, so her GP referred her to Cardiff Royal Infirmary. From there, she was sent to Chepstow Hospital in an ambulance, to undergo plastic surgery on her face.
12. The first procedure my mother undertook was the stitching of her left eye. She had completely lost her sight in that eye. I believe this was due to the shingles damaging the nerves in her eye.
13. After this, a skin graft was taken from the inside of her leg and placed on her face to repair the facial tissue damage caused by the shingles. The skin graft took well and the operation was a success, although she had to wear a big eye-patch on her left eye from then on.
14. I do not remember whether she received any blood transfusion during her plastic surgery. Nor can I remember the names of the doctors who were responsible for her health care at Chepstow Hospital.

15. To the best of my recollection, she was discharged after a year, but had to attend weekly check-ups at the Royal Infirmary in Cardiff. These consisted in checking her face to see whether the skin graft had taken and that the skin was healing properly.
16. Shortly after, her stomach started to swell, and her face and eye became bright yellow. I believe this was in 1966, although I cannot remember the time of the year. My mother went to see her GP, Dr Gulliford, who prescribed water tablets. As Mum's health did not improve, she went back to Dr Gulliford, and was referred to the Royal Infirmary hospital in Cardiff.
17. I have a distinct recollection that she was so yellow that her face blended in with the mustard colour of the hospital wall next to her bed. This image always stuck in my mind.
18. I do not remember who was responsible for her care. She had a liver biopsy, which confirmed that there was something wrong with the liver, although I cannot remember what. I do not know the exact treatment she was placed on either. She stayed at the hospital for a couple of months, and I visited her everyday. When she was discharged from the hospital, she was prescribed some tablets, but I do not know what they were.
19. My mother was well enough to come home, but she never seemed to have fully recovered. She had no energy, lost a lot of weight, and became very absent minded.
20. In summer 1968 or 1969, Mum's general health further deteriorated. Her stomach was swollen again, she lost an incredible amount of weight, and had no energy. She was so unwell that she was unable to care for herself, and I became her full-time carer. My father continued to work to

provide money and food for the family. My mother remained in this condition until 1973.

21. In the summer of 1973, I was camping in Devon when my father contacted me and said I needed to come home. My mother's health suddenly deteriorated dramatically, so he had to take her to University Hospital Wales, where he worked as a charge porter. I will refer to this hospital as the "Heath Hospital", as it was commonly called at the time.

22. I cannot recall the exact treatment my mother received at Heath Hospital, but I know she received several blood transfusions. I really cannot remember how many she had, or for how long she received them, but I remember seeing the drips coming from a bag of blood, which hanging from a pole and connected into her arm. Her blood was also regularly taken, I believe to be tested.

23. I visited her on a daily basis. I would help her wash, dress, eat and even go to the toilet. I would also bring her food three times a day, as she could not digest the food that the hospital gave her. My father would then take over after his work shift in the evening and come home once she was asleep.

24. Shortly after she started treatment, Mum told me there was something wrong with her. With hindsight, I believe this is when she was diagnosed with 'hepatitis', although the doctors may not have known the full diagnosis or effects on her.

25. My mother told me that I was not to use anything that she had used (i.e. cutlery, flannel, cup, saucer, plates, etc.), because I could get infected with her illness. She also asked me to wash my hands after touching her. I had to take special care at all times. For instance, I would boil the flannels used to wash her, and wash her clothes in the washing machine twice.

26. She was also moved from an eight-bedder room to a single room. I was never told why, but in hindsight, I believe this was to avoid contamination to other patients and staff in the hospital. She stayed in ward A7 under the consultancy of Dr Rhodes for almost four years.
27. In early 1979, during one of my daily visits, she started coughing and heaving. I told the senior nurse, Olga (Thurlow), who was in the room, that my mother was going to be sick. Olga sat her up and I held a tray under her chin. My mother was sick, and I heard Olga say: "*Oh my God!*". On the tray was some blood and a black lump as thick as an old penny (i.e. about a quarter of an inch). Olga identified the lump as being part of my mother's liver. This whole scene was awful and shocking. Olga called for help and asked me to leave the room.
28. I waited in the restroom whilst others assisted Olga. I was in a state of shock. I thought I was going to lose my mum. I wish I could have gone to find my father, but I knew he was working and that I should not disturb him.
29. After the doctor came in, I was allowed back into the room. I could see that my mother's bedding had been changed. She seemed a bit better, but her mental faculties had gone, and she was going in and out of consciousness.
30. I was really shaken by this incident, yet no one came to speak to me and explain what had just happened.
31. When my father came to my mother's room in the evening to take over her care, he was livid. He was really angry that no one had told him what had happened to Mum until then. He was furious and really upset. When he got home that night, I asked him: "*Is everything alright?*" and

he said: "Yes." However, the following evening, I asked him again and he said: "*I do not think she is going to last; she will not get over this*".

32. During the following weeks, my mother was constantly drifting in and out of consciousness.

33. One evening, my father told me: "*You'd better go home*", which I did and had a cup of tea. When my father got home, I asked him: "*Dad, are you alright?*" and he said: "*No*". I asked him why, and he said: "*She's gone, Bill*". He put his head in his hand and said: "*She's dead*". She was fifty-eight years old.

34. My father went back to the hospital and said he would not be long, and that when he came back, we were going to talk. When he returned, he told me there had been an autopsy of my mother's body. He said the doctors opened her head and took her brain out to examine it. He told me about the white stitches that had been left on her head.

35. My mother was then placed in a sealed coffin. The hospital staff (I cannot remember whether it was a doctor or a nurse) told my siblings and I that we could not see her because she was highly contagious. My mother was then sent to the crematorium, in line with our family wishes.

36. The following day, I reported my mother's death to the authorities and obtained a death certificate dated 7 February 1977. My father and I read it, but we did not understand what the causes of death, especially 'hepatitis' and 'infective hepatitis' meant in lay terms. We did not ask doctors what is meant, and I do not think they really understood my mother's disease either at the time.

37. I was never personally provided any information regarding my mother's infection and illnesses by the doctors. The medical staff would speak only to father. He chose not to share anything with me, but I believe this

to be a protective measure; he tried to shield me from the worst. I wish doctors had explained to me what was happening to my mother, as I was a young adult at the time and old enough to understand.

38. I was never tested for HCV, even though I was exposed to it on a daily basis whilst caring for my mother. I was tested years later, when I became a health carer, because it was part of the requirements to take up employment. Thankfully, my results came back negative.

39. I do not believe my father and sister were tested either. I think we should all have been tested, because we were constantly in contact with her.

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

40. I am not aware of any infections other than Hepatitis that my mother would have contracted as a result of blood transfusions.

### **Section 4. Consent**

41. I do not believe that my mother was treated without her knowledge and consent. However, I do not think she, nor my father, would have fully understood the information provided to them, as neither of them were well educated.

42. I do not know whether my mother was tested for Hepatitis or other infections with or without her consent.

43. I always said my mother was a guinea pig, because the doctors were changing her medication on a regular basis. I remember them saying: "*Let's try this*" and "*Let's try that*". If there was anything new on the market, they would try it on my mother.



## **Section 5. Impact**

44. My mother suffered greatly, physically and mentally. As previously, after her episode of jaundice in 1966, she became very absent minded. She never used to be like this before. I remember once, she went to the shop, placed groceries in her basket and went home without paying. I later received a call from the shopkeeper asking me to come and pay. I wonder whether this absent mindedness was due to the medication she was taking at the time. In any event, this meant that she was never able to go back to work.
45. To help with her recovery, she spent some time at different convalescent homes. In 1966, she stayed at William Nicoll Convalescent Home, Cardiff. In around 1968 or 1969, my family and I went on holiday in Clevedon, Somerset. My mother stayed in a convalescent home, whose name I cannot remember. My father, my sister and I camped nearby, so that we could spend time with my mother and provide her with moral support during her recovery.
46. As previously mentioned, she became really ill when we returned from Somerset. She could not go up the stairs on her own. She lost an incredible amount of weight; she had no flesh on her body. She used to be so feminine; it was really upsetting to see her like that. She was gaunt, and just a shadow of her former self. She had no energy and would fall asleep at the drop of a hat. She also had a lot of wind, and was noticeably very absent minded. She would stand by the sink in the kitchen at our home and wonder where she was.
47. She was so ill that she could not do anything on her own, and required full-time care, which I provided. Whilst she appreciated everything I was doing for her, I believe she felt embarrassed, humiliated and guilty for it.

48. During her stay at the Heath Hospital, she undertook biopsies after biopsies to monitor her liver. The injections used during the biopsies would leave nasty scars on her body, which I could see when I would wash her. Her blood was regularly taken, I assume to be tested for infections. She was covered with yellow and blue bruises all over her body, as nurses would have to find points where to take blood from, other than her arms. She also undertook three lumbar punctures. It was a really painful procedure for her; she also told me the needles felt blunt. I also remember that she used to pee a blue colour, I believe as a result of the medication she was taking. I saw this myself, as I used to help her go to the toilet.

49. I do not recall my mother facing any stigma due to her infection, because nobody outside the family knew. We kept this within the family, like a sealed coffin. However, on the occasional day releases, if we ever visited friends or family, she would take her own cutlery, saucer and flannel in a bag. I believe this was to prevent contamination. I do not remember whether anyone noticed or asked any questions in relation to this.

50. I also remember an incident which occurred after Mum's plastic surgery. We were taking a bus together. I saw a man staring at her eye patch. This really upset me GRO-C  
GRO-C

51. I do not believe my mother ever faced difficulties in obtaining treatment. I believe the medical staff in the various hospitals she attended always did their best. I do not recall any issues surrounding her dental care either.

52. My mother's illness had a tremendous effect on my life. I became my mother's full-time carer around 1966. I was nineteen years old. My father was willing to assume that role, but as he earned more money

than me at the time, he asked me to quit my job as a painter-decorator and stay at home to care for my mother. I happily did so, as I loved my mother and would have done anything for her.

53. In the morning, she would sit on the side of her bed and wait for me. I would help her wash, dress, do her hair and cook for her. I had to be extremely careful when handling her because she also had “crumbling bones”. In today’s medical terms, a comparison would be osteoporosis. It was a complete role reversal: she was like a child, and I became the parent. I still have flashbacks of this period of my life.

54. It was also difficult not knowing what was wrong with Mum. I know my father tried to protect me, but I wished I had been made aware of what was going on. Over the years, I witnessed some shocking and distressing scenes, like the time she vomited part of her liver, but no one ever spoke to me, asked me whether I was okay or provide any counselling.

55. When she died, I was devastated that I couldn’t say goodbye to her. I keep seeing her on her bed. I miss her everyday.

56. Six years after she died, I received an orange card (i.e. the forerunner of the blue badge scheme) for my mother. Despite this being a clear mistake, people need to understand how insensitive, humiliating and disgraceful it felt at the time. It really upset me.

57. Of course, having to care for my mother in my early twenties meant I could not work. My father provided for everything. However, caring for my mother taught me valuable skills, and I became a professional health carer later on in life.

58. The impact on my father was terrible. When my mother was an inpatient at Heath Hospital, he would work all day and then stay up with her,

holding her hand, sometimes until two o'clock in the morning. He was not the sort of man to speak or share his feelings, but I could see how painful this was to him. I remember he would often put his head in his hands and cry.

59. Losing my mother killed him. When he lost her, he also lost the will to live. He felt so guilty for not being able to save her. He was diagnosed with cancer of the colon shortly thereafter, and died seven months after my mother passed.

60. I am unaware of the impact my mother's illness had on my brother, because I was never really close to him. He always stayed away from the family.

61. My sister on the contrary was really upset by my mother's death, as she was close to my parents and me. She was not living with us at the time as she was married, but she would come on holiday with us.

62. I have lived with this tragedy for 40 years. When I saw in the *South Wales Echo* that the Infected Blood Inquiry was holding public hearings in Cardiff at the end of July (2019), I decided to come along. After speaking with a member of the Inquiry Team, I decided to provide a witness statement, because I wanted to tell my mother's story, and for people to know that this should not have happened.

63. Providing a statement to the Inquiry has been an extremely difficult experience for me. It has brought back extremely painful, emotional memories to the forefront of my mind, which have kept me up at night. I have fought through the pain in order to tell my mother's story and honour her memory. However, this experience has left me feeling very upset, unsettled, distraught and angry.

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

64. I do not believe my mother faced any obstacles in obtaining treatment.
65. I do not believe she was ever offered any psychological support, and I do not know whether it would have helped her.
66. I was never offered any counselling or psychological support, but I do not think it would have helped me.
67. The Inquiry investigator has made me aware of the assistance available from the British Red Cross to those who have been infected and affected by the contaminated blood scandal. I have been provided with the British Red Cross' counselling details, and will consider whether I will use their service in the future.

## **Section 7. Financial Assistance**

68. My family and I did not receive any financial assistance, as there was nothing in place at the time. As such, I do not have anything to say about the Trusts and Funds set up to distribute payments to people infected and affected by the contaminated blood scandal.

## **Section 8. Other Issues**

69. I have not been part of any litigation or campaigning in relation to the contaminated blood scandal.
70. All I want to say is that I miss my mother terribly. I would have done anything for her.
71. I want to know who is to blame for this contaminated blood scandal. I want justice for my mother and the people who have suffered. It should never have happened in the first place and should never happen again.

The blood should have been tested at the point of origin and when it got to the UK. I believe the medical staff assumed that the blood was tested. This should have been checked and double checked. Somebody must be held accountable. No lies, just truth.

**Statement of Truth**

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

Signed GRO-C\_\_\_\_\_

Dated 25/09/19