

Witness Name: Diane Elizabeth Middleton

Statement No: WITN1392001

Exhibits: 0

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DIANE ELIZABETH MIDDLETON

I, Diane Elizabeth Middleton will say as follows:-

Section 1. Introduction

1. My name is Diane Elizabeth Middleton. My date of birth is GRO-C 1966. I am married and live at GRO-C I have three children; the two elder ones are married and live in their own homes and my stepdaughter still lives with us.
2. This witness statement has been prepared as the sister of Graham Edward Fox who was infected with HIV from contaminated blood. I have prepared this statement without the benefit of access to my brother's medical records.
3. My brother was 14 years old when he tested positive for HIV. He was born on GRO-C 1970 and died from AIDS on 23 April 1996. He was 26 years old and was living at my house when he died.
4. I am left with no other siblings. Our mother passed away 6 months before my brother died. In later years, our father had little or no involvement with

his welfare. During the critical months before my brother's death, I was his main carer.

Section 2. How Affected

5. My brother was 1 years old when he was diagnosed with severe Haemophilia A. From the ages of 1 to 6 he was treated at The Royal Victoria Infirmary (RVI) in Newcastle and from the ages of 6 to 11, he was transferred to Wellburn Hall School, Kirby Moorside in York. I do not know the names of the doctors who treated him up to the age of 11 but I do know that they found that he was allergic to Cryoprecipitate Plasma and Elastoplast. For this reason, they had to treat him with Koate-DVI even though I believe it was not particularly effective.
6. From the age of 11, he was under the care of Dr Peter Jones and from 14 onwards he was transferred under Dr Peter Hamilton.
7. Graham was shown how to inject at Welburn Hall School, I assisted him whilst he was at Whitburn comprehensive.
8. At some stage during his secondary education, my brother began to suffer from severe nose bleeds. For this reason, the doctors decided to treat him with Prophylactics which was to prevent the bleeds from occurring rather than to stop them. My brother started to regularly inject himself with this product and I think this helped him.
9. Nonetheless, my brother continued to regularly attend hospitals and was seeing doctors out of hours when he had spontaneous bleeds.
10. I believe my brother contracted HIV due to the FVIII products used to treat him and he eventually died of AIDS. The NHS is responsible because I believe that the FVIII blood products were contaminated.

11. By letter dated 23 January 1996, the NHS sent a letter to our solicitor in which it admitted that the HIV contracted by my brother was caused by the injection of FVIII products used to treat him. The letter states;

"a 25 year old man has a genetic condition associated with spontaneous bleed inter-joint. In order to prevent crippling, has to inject Factor VIII blood concentrate to stop a bleed whenever it occurs. Tragically, he has received HIV virus from an infected Factor VIII concentrate and has himself been infected with HIV since 1984".

Section 3. Other Infections

12. My brother had contracted Hepatitis C and Pneumocystis Carini Pneumonia (PCP). He experienced excess sweating during the night, weight loss, diarrhoea and general disability.

13. By a letter sent to myself in March 2011, the NHS admitted that my brother had contracted Hepatitis C as well as HIV. My brother did not know about Hepatitis C because no one at the hospital had advised him or my mother.

Section 4. Consent

14. I believe my brother knew that he was being treated with Factor VIII blood products.

15. I believe my brother was not informed that the FVIII blood products were contaminated. I also believe my brother was never informed of any risks involved with being treated with contaminated blood. If he had, he could have made an informed decision as to whether or not he wanted to take the risk of being infected with HIV.

16. If he had been informed, I am sure he would have discussed this with my mother and also sure he would not have agreed to his life being put at risk.

Section 5. Impact

Impact on my brother

17. I do not know whether my brother was accompanied when he found out he had been tested positive for HIV. I know he tried to remain positive but I recall that his mood drastically changed when he was informed that he would not be able to travel abroad due to his condition. I know he used to get excited about going on holidays but suddenly this was taken away from him. He did not want to live his life with this restriction and I think he was never the same after he was told.
18. My brother and I moved out of the family home at an early age and this was due to GRO-C I was placed in care at the age of 15 and I began to live away from my parents. As a result of this, my brother and I were also separated. He often came to stay with me during this difficult period. To ensure we maintained contact, my brother used to cycle to my house. He liked to do this because it helped his arthritis. This was about the time he had just started secondary school.
19. After secondary school, he went to college and was able to secure employment as a computer programmer. He wanted to succeed and was aware that the key to success was doing well academically. He seemed to be able to keep his medical condition a secret from the college tutors and I do believe that his friends at college were also unaware that he had HIV.
20. When he went to work, my brother concealed bruises from his body because he did not want to have to explain his condition to them. I know this worried him because he often panicked when his bruises could be seen by others.
21. He tried his best to put all his energy into his work and did his best to make things better for as long as possible. By the age of 24, however, his health deteriorated to such an extent that he had gave up his employment.

He began to suffer from anxiety and this merely added to his worries. When he ceased work, he attempted to commit suicide on a number of occasions.

Impact on me

22. In the early 1980s, I became concerned about the future of my children. I was aware I was a potential carrier of haemophilia and for this reason I contacted the hospital wanting to know whether or not there was a risk of passing my gene onto my own children.
23. When my brother came to visit me, I had to continuously clean up blood spills and protect my own children from being infected. When I look back, I had no gloves etc. to care for my brother when he needed me.
24. I avoided questions about my brother's condition. This was because we received a lot of abuse from local people who would scratch our car to intimidate us. It came to a point when my brother would sleep with a baseball bat by his pillow because of the threat.
25. Rumours at the time started very easily especially with the media attention given to AIDS. We were afraid to tell teachers at school as we did not know how they would react. I had to teach my children to be secretive about my brother's condition because of the stigma attached to it and I did not want them to be bullied.
26. In the last months of his life when my brother moved into my house, I found it very difficult to care for him. Physically and mentally he became so weak that he could not get in and out of bed. This made it very difficult for me to manage his personal hygiene.
27. At this time, I was divorced. Apart from managing my own children who were 11 and 13, I took responsibility of caring for my brother as there was nobody else to do so. Sadly, he had developed dementia, lost cognitive

abilities and was unable to sleep. The hospital prescribed him morphine which I had to regularly collect.

28. My children's education was affected by my brother's illness.

29. My brother's final few days were spent at hospice. I would have to bathe him because he would not allow the hospital nurses to do so. I slept at the hospice and a local charity helped us with anything we needed.

30. We were advised that AIDS would not be on his death certificate. We were informed that this would protect us from harassment.

31. After my brother died, I felt exhausted and struggled a lot. I suffered from severe depression. The last 4 months of his life was very traumatic both for me and my children. They were told that my brother suffered from haemophilia and was infected with HIV that had developed into AIDS. They knew that they had to be careful and were aware that my brother had spontaneous diarrhoea and nose bleeds.

32. My children and I struggled after my brother died. I could not cope and was diagnosed by the GP with clinical depression. I was prescribed antidepressants which carried on for a few years before I could go back to work.

Section 6. Treatment/Care/Support

33. For dental treatment, my brother had to see a dental specialist at hospital.

34. As far as I am aware, my brother had no difficulty in accessing treatment. However, when he came to live with me in Yorkshire, he was very ill. I had to pick up morphine from the RVI to bring to the house as the local GP would not provide any assistance. The GP told us that he was not

prepared to go near my brother because he had AIDS and that he was only prepared to pronounce his death.

35. In 2011, the hospital informed us that my brother had contracted Hepatitis C and that we may qualify for payment from the Skipton Fund. This was followed by a letter from the Haemophilia Centre advising that the family could apply on behalf of his estate.

36. I was not offered any counselling before or after my brother's death and this had to be requested. I was given anti-depressants and received counselling. A local charity arranged for GRO-C

GRO-C

37. My brother was also received counselling. I know that a psychiatrist wanted to place him in hospital under Section 18 of the Mental Health Act because of his suicide attempts. However, after some consideration it was decided against taking this course of action because his behaviour was deemed to be normal in the circumstances. The counselling did help him cope to some extent.

38. The hospital gave us no information or advice about the risks of being treated with contaminated blood. I believe the doctors were aware of the risks long before my brother passed away.

39. My Aunt provided me with support. She telephoned frequently when my brother was in hospital. We took shifts to take care of him. I also received support from the local AIDS charity.

Section 7. Financial Assistance

40. My brother received a lump sum of £30 000 in 1992 but I do not know who paid it. I also know he received a monthly sum but I do not know how much he received.

41. The Haemophilia Centre advised my brother how to make the applications for payments. I am unaware of any difficulties, obstacles or preconditions he may have had with the relevant applications.
42. The Macfarlane Trust made a payment for my brother's funeral costs. I do not know the amount that we received. I do know, however, it covered all the costs.
43. I received two payments from the Skipton Fund for my brother's estate. On 10th August 2011, I received £20,000 because he was infected with Hepatitis C. On 27th August 2013, I received £50,000 due to the fact that he would have developed problems as a result of having been infected with Hepatitis C. The money came to me as next of kin and I am the executor of his will. I found about the possibility of receiving these payments when the hospital wrote me a letter on 1st March 2011 stating that I could apply.

Section 8. Other Issues

44. My brother was involved in the original 1990 Litigation. An individual claim was brought on behalf of his estate. I believe the case was settled out of court but I do not know how much he received.

Anonymity, disclosure and redaction

45. I confirm that I do not wish to have anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

46. I do wish to be called to give oral evidence.

Statement of Truth

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

Signed.....GRO-C.....

Diane Elizabeth Middleton

Dated 25th January 2019