

Witness Name: Tessa Lee
Statement No: WITN1344001
Exhibits: 0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TESSA LEE

I, Tessa Lee, will say as follows:-

Section 1. Introduction

1. My name is Tessa Lee. I was born on [GRO-C] 1975 and I live at [GRO-C] [GRO-C] Manchester [GRO-C]
2. I write this statement on behalf of my late father, Derek Hope Lee. He was born on [GRO-C] 1933 and died on the 13 April 1988 aged 55 from AIDS and Hep C. I was just 12 years old when my father died as a result of the infections.
3. I currently live on my own and have a 19 year old daughter. My mother is still alive, living with my stepfather whom she has been with since I was 4 years old. My sister, Anna and I are adopted and we share the same father. We were adopted from different families.
4. My mother and father adopted us instead of having biological children as he did not want his biological children to suffer from Haemophilia like he did.
5. I suffer from mental health issues and am receiving mental health care. I believe my mental health issues started when my father was diagnosed with

the infections and I believe it got worse after his death although I was not aware of this diagnosis until later on.

6. This witness statement has been prepared without the benefit of access to my late father's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

7. My father suffered from severe Haemophilia A. He was receiving direct blood transfusions from his father as a child and then started to receive Cryoprecipitate, followed by Factor VIII (FVIII) to treat his bleeds.
8. My father was an educational psychologist. He was physically able to live a normal day to day life until the early 1970s when he fell down some concrete steps at the school where he was teaching. He bled through his knee caps and I do not think his knee ever healed as his Haemophilia was so severe. He kept having surgery and had a crooked leg.
9. My father was mainly treated at the Haemophilia Centre at Manchester Royal Infirmary (MRI). It could be any time from when he received FVIII to when he was diagnosed that he was infected with HIV and Hep C.
10. In 1987 I believe he was diagnosed with HIV. I believe he was told 6 months prior to his death in 1988 as this is what my mother told me a few weeks ago. I believe my father rang my mother and told her he was infected with HIV and that he wanted to tell me and Anna. However, my father never got the chance to tell us as he died too soon.
11. I believe that my father was also infected with Hep C. However, I am not sure when he was told or what information was provided to him about the infection. I do not know if he received any information about how to manage the infection.

12. I remember my father constantly had thrush in his mouth and I believe it was as a result of the infections. I know he was in and out of hospital but never really knew what it was for.
13. My father remarried and was living with my stepmother during the time that he was diagnosed with HIV. My stepmother had a hospital bed downstairs for my father and he had bed baths at the back of the house. She also had a stair lift to assist my father. This was close to his death when he was really poorly and had become skin and bones.
14. I believe that no information or advice was ever provided to my mother at that time. My mother worked as a nurse in the NHS and worked her way up as director of all clinical services in Stockport. However, even she was never told of the risks associated with contaminated FVIII.
15. I do not believe that adequate information was provided to us about my father's infection and I believe it should have been provided earlier.
16. I believe my father was given some information as to the risks of passing the infection onto others. I know this because when I was about 11 or 12 years old, he dropped a swab with blood on it on the floor and he asked me to pick it up carefully by using my fingernails. I remember him emphasising not to touch the blood and he said it about 5 times.

Section 3. Other Infections

17. I am not aware that my father contracted any other infections as a result of infected blood products. I have never seen his medical records.

Section 4. Consent

18. I believe my father was treated and tested without his knowledge and definitely without his consent. I am not sure whether my father was given adequate or full information about the infection but my mother was not.
19. I do not know whether my father was tested for the purposes of research.

Section 5. Impact of the Infection

20. My father suffered from the physical effects as a result of the infections. Slowly he went from using a walking stick, to crutches, to a wheelchair and then he was bedridden. He became weaker and weaker in front of my eyes. The infections took over his body. He also had thrush in his mouth and I believe it was as a result of his infections. I also remember he had a commode and urine bottle next to his bed as he could not get up to go to the toilet.
21. My father also suffered from mental effects and he was not able to live a normal life once the infections made him poorly. Sometimes he wanted to come into the living room where we used to watch TV but he would be too sick to do so. I therefore went to his room to be with him and watch TV with him which would make him feel better.
22. His behaviour really changed and at one point he would not even tell me off when I misbehaved. There was an instance when he cried for the first time and I still feel guilty now because I should have behaved better back then. He could not bare to tell me off as a father would, as I believe he knew he was going to die.
23. We were told not to go near my father whenever he had a bad cold. My father was very good at hiding his feelings and emotions. He made it seem like everything was fine and that nothing had happened. He was always my safety place and I just love him so much that it hurts to know he is gone now. He absolutely adored us and he was my favourite person in the whole world.
24. I do not know what treatment my father was given for his infections. However, my mother did tell me that my father had mental and physical effects as result of all the drugs he received and that it made him even worse. He became more bedridden and he could not attend any of our school functions and take us on holidays. It must have broken his heart to not be able to come on holidays with us and enjoy it. Prior to his infections and treatments, my father

used to love taking us on holidays and coming into school to see what we had achieved.

25. My father's death impacted me tremendously. The day he died, I had been ringing my stepmother [GRO-C] My father's best friend, picked up the phone and when I asked to speak to my father, he kept changing the subject. I did not argue and just came off the phone. I thought his reaction was strange.

26. Later, my stepmother phoned us and spoke to my mother who started crying when she heard the news. My stepmother and mother have never spoken over the phone before, so I knew something was wrong when she called.

27. I felt so lost as the most precious person to me was gone in the blink of an eye. Anna also left the house for about 3 days. She struggled to come home as she could not bare the thought of our father being gone forever.

28. It has been 31 years since my father died, but I have never got over it. My life is like a whirlwind right now, I cannot settle and I have been so ill.

29. I suffer from Post-Traumatic Stress Disorder (PTSD) as a result of my father's death. I have borderline personality disorder and bipolar disorder traits. I attempted suicide in May 2018 and the police had to break into my house. Everything on the news about the Inquiry has overwhelmed me and I just wanted to go and be with my father. I then felt guilty for my daughter and mother as I thought that if I had committed suicide, they would have to live without me. I am now waiting to be given level 3 of Cognitive Behavioral Therapy CBT.

30. I am receiving counselling now. I never went back to school again after the age of 12. When I get so upset about anything, I revert to that 12 year old person who just wants to see her father. I currently suffer from anxiety and have scarring as a result of self-harm. I have never had bereavement counselling or any intense counselling. I sit here having to deal with my own demons.

31. Due to my mental health, whenever I have a very bad episode, the crisis team come to my home and I have to present myself at hospital and let the mental health team decide what to do with me to keep me 'safe'. I even have a police record. My daughter has been affected as a result of my mental health, as well as my sister and my mother [GRO-C]

32. As a result of my father's death, I have developed a mind set that if I do not love anyone and they do not love me, then nobody gets hurt. I have never had a loving relationship with anyone, both with friends and intimately and even my daughter does not live with me anymore.

33. My ex-partner, my daughter's father was not the right person for me and so we broke up. During this time I was so vulnerable and started dating a person who I knew was not good for me. We eventually broke up [GRO-C]

[GRO-C]

[GRO-C] I also changed my name by deed poll. I have had bad relationships throughout my whole life as a result of my father's death, with whom I had the best relationship ever.

34. We did not even get to go to my father's funeral. I recall my mother saying if we attended the funeral, we would be sitting at the back because of my stepmother. I was so upset about it because I wanted to go. He was my father and I wanted to say goodbye.

35. I was a bright and enthusiastic 12 year old starting secondary school before my father died. On 22 March 1988 I lost my grandfather. Until his death, I had never experienced death before and was grieving but not even a month later my father died. It was too much pain to go through and I could not go through with it anymore. My father's death ruined my education completely.

36. I ran away from home at 13 and never really came back properly. Police were involved a lot in my life as I ended up robbing my mother's TV. Once, I stole the entire contents of the freezer and wheeled it to my friend's house for the sake of it because I was so angry. I was sleeping all over the place mainly at

my friend's house. My mother did not change the locks on the house so I was always able to come home and take anything that was not nailed down.

37. My life has been horrendous ever since. Having my daughter was the best thing that ever happened to me in my entire life. I have been through so much trauma and I cannot even talk about it without crying.

38. However I need to make this statement for my father as well as my mother who was left with two traumatised teenagers.

39. I get really emotional when it is someone's birthday or Christmas. I ache just to say goodbye to my father. I did not just lose my father but my best friend. We used to go out together every weekend and do fun things. The whole disease just ravished him and took everything from him.

40. Back in those years, there was a stigma attached to HIV. People used to bully others and say horrible things like 'I hope you get AIDS and die'. The media made it seem as if infected people were promiscuous or drug users and so I never told anyone. After reading this once in the papers, I had a panic attack and had to go into the surgery, where I was prescribed diazepam to calm me down. The stigma attached to the HIV therefore affected me and my family. It continued even after his death. Whenever I heard the word HIV or AIDS, I would want to defend these people but could not as they did not know my father died of AIDS.

41. I remember I was about 13, and I overheard Anna asking my mother whether our father died of AIDS. I came down and asked why they were talking about AIDS and I was told to ask my stepmother who said our father died of kidney failure. I had a hint that he died of AIDS but no one told me until I turned 18 years old and compensation money started to come in from the Macfarlane Trust. It made me angry that the truth was kept from me for so long.

Section 6. Treatment/care/support

42. I do not know whether my father faced any obstacles in receiving care and support and I do not know whether he was offered any treatment.

43. I was offered counselling and psychological support with a child psychiatrist at one point. I remember being so damaged that I would not even engage with the counsellor and I shouted at my mother asking for the car keys and blackmailing her to break into the car if she did not give me the keys.

44. I believe if I was offered proper counselling or psychological support, it would have definitely helped me get through some of my pain that I was going through.

45. My mother was never offered any support or counselling as a result of my father's death. She did not know how to bring up two children who had been so traumatised and she struggled. I therefore believe that some counselling, guidance and support would have helped her as she carries a lot of guilt.

Section 7. Financial Assistance

46. In 1993 when I had turned 18 years old, I received £5,000 and I believe it was from the Macfarlane Trust.

47. I believe that for all that we have suffered, my mother, my sister and myself should have received ongoing financial support.

48. My stepmother and her children went on holiday to Thailand after my father died. Anna and I did not get an invite or a holiday and she never gave my mother a penny towards our upkeep after my father died. She was left a 4 floor 5 bedroom house with 2 bathrooms which was free from a mortgage. She had enough money from my father's death to go on fabulous holidays and set up her own school for the blind and partially sighted children.

49. We want our father back but it hurts to see them all so settled in their futures while Anna and I do not have that security. It is upsetting.

Section 8. Other Issues

50. I had no knowledge of this scandal as no one has ever provided me with any information. All I know is what I have seen on the media, and what I had to

deal with. It is so heart breaking knowing that I never got to say goodbye to my father.

51. Whoever was responsible for my father's death had no right to give him infected blood products. It is beyond words and I can not comprehend it.

52. I expect those people responsible for my father's death to be held accountable for such a despicable act. They killed someone who was so important in my world and no one has the right to do that to anybody. What they did was cruel and I want answers for it. My father was so shattered that he could not even sit down and tell us that he got AIDS. He was so broken and we never got to say goodbye to him.

53. I want to know who allowed this scandal to go ahead. I want to know how they would feel if I infected one of their family members with infected blood products.

54. We have been robbed of a chance to a normal life, career and everything. I want those who are responsible to know how broken inside it makes me feel.

55. It is appalling and shocking that the government allowed all of this to happen in the first place and I would like answers from them.

Anonymity, disclosure and redaction

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

57. I wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... GRO-C

Dated *22nd february 2019.*