

Witness Name: Sheila Ford
Statement No: WITN1221001
Exhibits: WITN1221002-004
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SHEILA FORD

I, Sheila Ford will say as follows:-

Section 1. Introduction

1. My name is Sheila Ford. My date of birth is GRO-C 1948. My address is GRO-C
GRO-C Leicester, GRO-C I am retired and
I have been divorced for 24 years. I have a 45 year old daughter and two
grandchildren.
2. I am a Haemophilia carrier, so I only had one child. GRO-C
GRO-C
3. I had four brothers, but only two of these are still alive. My older brother is called
Michael, and then I have a younger brother called Jeff. My next youngest brother
was Ron who died 5-6 years ago, and my brother Alan was the youngest.
4. GRO-C

Section 2. How Affected

5. I am making this statement in relation to my younger brother Alan David Smith, whose date of birth was GRO-C 1957. Alan died on 29th June 1996. Alan had severe Haemophilia A. Alan regularly had bleeds on his joints and nose bleeds.
6. Alan was single and lived at home with our Mum and brother Ron. When he first left school Alan worked in a record shop. However, he didn't manage to work for long as he was so unwell with his Haemophilia he had to stop working. He then claimed disability benefits.
7. Alan received treatment with Factor VIII at Leicester Royal Infirmary to treat his Haemophilia. On one occasion, Alan was treated at Derby Royal Infirmary.
8. I exhibit at WITN1221002 Alan's National Haemophilia Database records which show the treatment he received between 1976 and 1996.
9. I don't know if Alan was ever provided with any information or advice about the risks of being exposed to infection from receiving blood products.
10. Alan was infected with HIV and Hepatitis C. We only discovered this once he died from his death certificate.
11. I was unaware that Alan was being tested for HIV before he died. From Alan's medical records I have discovered that he tested negative for HIV on 03.09.83. However, he then tested positive on 31 January 1985.
12. I am not aware of how Alan found out about his infections and the extent of the information he was given. Alan was a very private person.

Section 3. Other Infections

13. I am not aware of any other infections that Alan contracted as a result of receiving contaminated blood products.

Section 4. Consent

14. I do not know whether Alan was treated or tested without his knowledge, consent, without being given adequate or full information or for the purposes of research.

Section 5. Impact of the Infection

15. I saw Alan every week and as time went by he started to look more and more unwell. I put this down to his Haemophilia. He would say things to try and make me guess what was wrong with him, rather than actually telling me. I remember him saying "I've got shadows on my lungs, what do you think that is?" I thought he probably had a chest infection or tuberculosis. It was as though he was covering it up and trying to protect us.
16. In the months towards the end of his life, I noticed that Alan became more unwell. He had always been so ill, so the family put it down to his Haemophilia. Alan was using two walking sticks for a few years and I struggled to get him in my car if I gave him a lift.
17. I do not know whether Alan received any treatment for his infections.
18. I do not know what impact Alan's infections had on his treatment for any other medical issues.

19. Alan became more unwell as time went by and in his final months he had to go into a hospice.
20. Alan used to have panic attacks and he was unable to go in lifts because of his anxiety. He told us he was going to a hospice for treatment because it had no lifts and was all on the ground floor. We believed this and did not think he was going there to end his life.
21. I was unaware that Alan was being referred to a psychologist for his mental health before he died until I received some of his medical records last year. I exhibit at WITN1221003 the records which refer to the deterioration in his mental and physical health towards the end of his life.
22. When I first applied for Alan's records Leicester Royal Infirmary said that they had been destroyed. They then sent me 4 letters dating back to 1994. In early 2019 I received a letter from NHS England which said they do not have any records as they had been destroyed, and that as they never received them it was likely that these records were disposed of by Leicester Primary Care Trust in accordance with the records retention policies in place at the time.
23. Looking back Alan sometimes appeared depressed.
24. It was a shock when Alan died, because we hadn't known about his infections. He hadn't let our family help or support him. We had many emotions about this. Alan went to the hospice late afternoon on the Friday and passed away just after midnight, so he was only there for a few hours. The hospice called to inform us that he had died.
25. Alan's death certificate states that he died of bronchopneumonia, chronic immunosuppression, and Hepatitis C –liver failure. I exhibit this at WITN1221004.

26. Alan did not tell anybody about his infections and became more secretive before he died. He went out with his friends and I think he wanted to keep everything as normal as possible. After he died, nobody seemed to have been aware of Alan's infections.
27. When the vicar discussed Alan's funeral with our family he asked if Alan was gay. He apologised when we told him Alan was a Haemophiliac.
28. The undertakers placed Alan's body in a black body bag and no one was allowed to say goodbye to him in the Chapel of Rest.
29. After he died I found out that Alan had been banned from his local social club because he had had a severe nose bleed there and someone had seen him as a threat to the public. I believe it was someone from the hospital who had him banned. It was part of his life to attend this social club and to go out as much as he could despite his health problems, so this would have been a real blow to him.
30. We did exactly the same as Alan did after he died, we didn't tell anybody outside the family about Allen's infections, as the stigma associated with the infections at the time was so bad.
31. We told people that Alan died from complications associated with his Haemophilia.
32. I have been left with lots of emotions about what has happened, in particular anger. Our whole family felt very emotional and very angry. We couldn't accept that the people we thought were taking care of Alan had done this to him.

33. Every time something comes up in the press or I have to talk about what happened to Alan for the Inquiry, it brings it all back. Although it has always been there, it brings it to the foreground of your thoughts.
34. I have close friends and sometimes I have surges of wanting to tell them, but it is very difficult. I am on the verge of confiding in one of my very close friends.
35. I do not think my mum ever got over what happened to Alan. She passed away a few years later. Jeff and I spoke to one another about it. It hit my brother Ron quite hard, because he was still living at home when Alan died and was his carer.
36. My daughter was in her 20's when Alan died, so she knew him.
37. I do not think there were any financial or work implications for Alan linked to his infections, because I believe he had already stopped working due to his Haemophilia when he became infected.

Section 6. Treatment/care/support

38. I do not know if Alan had any difficulties or obstacles in obtaining treatment, care and support as a result of his infections.
39. I have not been offered any counselling as a result of Alan's death.

Section 7. Financial Assistance

40. After he died I found one of Alan's bank statements which shows that he received £179 from the MacFarlane Trust. I do not have any other statements so I cannot state how regularly he received this payment.

41. After I found this, I got in touch with the Macfarlane Trust to see if I could find out more about Alan. They advised me to read one of their magazines and then call them back. When I did this, they asked me to go and see them. I went with my brother Ron and the Trust paid our travel expenses to go and see them.
42. The staff at the MacFarlane Trust told us to go to Leicester Royal Infirmary to ask for more information about Alan. We did this and had a meeting with a Sister Martin. She talked to us about Alan and what his wishes had been, i.e. that he didn't want his family to know about his infections.
43. Alan also received a one-off payment, but I cannot recall how much this was for. He told us this was for being a guinea pig for the doctors at Derby Royal Infirmary after he had a bleed on his spine.
44. I was the sole beneficiary in Alan's will. I received an ex gratia payment on 23rd June 2011 of £20,000 from the Skipton Fund. Later the same year on 15th September 2011 I received a payment of £50,000 from the Skipton Fund. I split these payments with my brothers.
45. Jeff found out that we could apply for the ex gratia payments through the Haemophilia Society. In order to receive this assistance, we had to provide a letter from the hospital to say that Alan had been infected with HIV and Hepatitis C.

Anonymity, disclosure and redaction

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.

I do not wish to give oral evidence to the Inquiry as I do not think I would be strong enough to do so.

Statement of Truth

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

Signed.... GRO-C

Dated... 21-2-2019