

Witness Name: M.F. Edwards

Statement No: WITN2683001

Exhibits: 0

Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARGARET FLORENCE EDWARDS

I, Margaret Florence Edwards will say as follows:-

Section 1. Introduction

1. My name is Margaret Florence Edwards of GRO-C Leeds, GRO-C I was born on GRO-C 1941. I have two brothers one younger sister. I am the second oldest.
2. I make this statement as the wife of the late Jack Edwards who was infected with hepatitis C and HIV as a result of being treated with Factor VIII blood products that was contaminated. My husband was born on GRO-C 1938 and died on 5 September 1985.
3. This witness statement has been prepared without the benefit of access to Jack's full medical records.

Medical records

4. I went to St James's University Hospital, Leeds (SJUH) just after Jack died to request his medical records. I was told if I made an appointment I could go to hospital and review his records in person. I did not make copies. I simply made a mental note of what I thought was important. At the time, it never crossed my mind that I would one day need to refer to them.
5. I just went to SJUH in Leeds because I needed to know for my own peace of mind how and why my husband died. It is now difficult for me to recall what records I saw. I had no idea that one day Jack's death would be part of an Inquiry.

Section 2. How infected

Family background

6. Haemophilia runs on Jack's side of the family. Jack suffered from severe Haemophilia A. His two brothers, John and David, also had the condition but were not infected with contaminated blood. They passed away but I do not know when.
7. I met Jack in the early 1960's. I found out shortly afterwards that he suffered from haemophilia. He suffered from spontaneous bleeds mainly from his joints. Whenever he suffered from a bleed he attended SJUH. As far as I am aware, in the very early days the hospital did not know how to treat him and the nurses would usually put him in a bandage and an arm sling. As a result, I would purchase Lead and Opium lotion from Boots Chemist as he would be in pain. The Chemist would stare at me wondering why I was purchasing that. My husband said that the lead had a cooling effect and the opium caused pain relief.
8. So far as I am aware, my husband was only ever treated at SJUH. I believe my husband received Factor VIII blood products which were supplied from

Armour & Company Pharmaceuticals. We used to collect the supply from the hospital and bring these back home when required.

9. Jack was using home treatment on demand. On average, he was treating himself two to three times a day. He was told to use these treatments and that he would be fine. We believe whatever the doctors told us. We received no information prior to receiving FVIII that these could cause an infection.
10. As far as I am aware the doctors never told my husband that he was infected with anything. He certainly never discussed with me that he was infected and neither did the hospital staff at SJUH tell me that I was at risk of being infected by Jack. Back in the day, there was no formal procedure in place to inform patients about their test results.
11. After Jack passed away, within a day or so Dr Swinburne told me that Jack was the second person to die like 'that' at SJUH and the doctor at the time said to me that only a couple more people may die from the same infection. She did not expand on what infection she was referring to.
12. I believe Jack was infected with hepatitis C and HIV sometime between 1975 and 1985. I do not know which of the two infections came first. The HIV did not turn into AIDS. It had not become full blown. It was the issues with his liver that ultimately caused his death.
13. Without medical records, I cannot say for certain what caused the infections. However, Jack's death certificate confirms the cause of death to be (a) Liver Failure, (b) Hepatic Cirrhosis, (c) chronic active Hepatitis and (d) Haemophilia. I believe the death certificate is sufficient evidence to support an argument that contaminated blood caused his death.

Section 3. Other Infections

14. I do not know whether Jack had contracted other viruses. If he had, he did not tell me and it certainly does not follow that he would have told me. The staff at

SJUH told me after Jack had passed away that he had Hepatitis C. I remember a consultation with Dr McVerry and Dr Swinburne who confirmed that the cause of death was a hepatitis infection. They provided me with no information on how or when he had been infected.

Section 4. Consent

1. FVIII products – I do not think the doctors advised Jack of the risks of infection through the use of FVIII products. If he had, he is unlikely to have consented to being treated by these products.
2. HIV – I believe the doctors tested Jack to see whether he was HIV positive and that these tests were carried out without his knowledge and consent. I do not know for certain whether the doctors treated Jack for this infection. If they did, I believe it was without his knowledge and consent.
3. Hepatitis C – I believe the doctors tested Jack to see whether he was infected with hepatitis. I do not think that at the time the doctors were aware that the infection was hepatitis C. I believe these tests were carried out without his knowledge and consent. I do not know for certain whether the doctors treated Jack for this infection. If they did, I believe it was without his knowledge and consent.
4. Research – I do not know whether the doctors tested Jack for research purposes.

Section 5. Impact of the Infection

15. Jack was not working when we met. I do remember that not soon afterwards he found himself a job as a Warehouse Foreman and he kept this job until the day he died. He never informed his employer of his haemophilia.
16. The job required lifting bulky boxes containing men's clothing. Jack was a diligent hard working person and did not believe in taking time off work unless

it was absolutely necessary. If his bleeds were serious he would come home to be treated. At the time, he was in his late thirties and early forties.

17. He stopped work only a week prior to his death. He told his employer he wanted to take early retirement which was agreed. Sadly, he never actually got to formally leave his employment or begin his retirement. His employers were however nice enough to keep him on the payroll for two extra days so that I could benefit from his occupational pension.

18. In 1985, his final year, Jack started to lose his appetite. He would take lunch to work and came home telling me he could not eat or digest his food so he gave it to a colleague instead. Jack used to love his tea, but towards the end of his life he said it tasted like poison to him. In the summer of that year, I would return home from work to find him shivering and encased in two thick duvets sitting beside the lit gas fire. This was very peculiar as it was very hot weather. Shortly before he passed away, his stomach began bulging. He used to wear 34 inch waist trousers and this increased to 44 inch which would only just about fit. I had to buy him new trousers as a result. Whenever Jack was poorly, I would be his carer. I would prepare his injections ready for him to administer and if he asked for something, I would go out and get it.

19. Jack would usually be admitted in Ward 34 at the SJUH and I have no criticism of this ward, however he passed away in Ward 32 which was an extremely hostile environment for me and my husband. On the night he passed away, I was called in and my husband was unconscious. There were fellow patients watching TV together however I was with my husband in a side room and I overheard someone say that it was disgusting to have my husband in the same ward and that he should be moved. They should never have known that he had HIV in the first place, but there was a label by his bed stating AIDS on it. The night he had passed away a nurse came around to take everyone's temperatures as she usually did, but by then my husband was dead. I consider it extremely incompetent that she still tried to take my husband's temperature. I told her not to bother as she was too late.

20. My children lost their father when they were still at school. My daughter Louise thought that everyone's father was the same and would often go for hospital visits like her father did. She was very sensitive. David on the other hand took everything as it came. He did not let it worry him until worry landed on his doorstep.
21. Not long after their father passed away, I went to Louise's school and spoke with the headmaster to discuss the behaviour of other children towards my daughter. Her classmates made fun of her for what happened to her father, but my daughter told them that she knew who her father really was and nothing they said could hurt her. Louise was strong like that and carried on.
22. I do not know if Jack knew he was going to die. If he had, I do not believe he would have told me. He was always positive and pushed our children to do well in their education. He considered their education to be of utmost importance as it would shape their future. The children only ever lost two days of school because of their father's death and Louise's school questioned that absence even though they knew her father had passed away. People just did not seem to understand.
23. I was distraught to lose Jack at such a young age. I lost my partner in life. If he had not been infected, we would still be together enjoying our retirement. After Jack had died, our neighbours started avoiding me. There was significant publicity given to AIDS in the media. I recall some of our neighbours would put their eyes down and walk straight past because they did not know what to say to me. They did not know how to react and I had to tell them that I was still here and not to ignore me.
24. Having to raise young children without the support of my partner was difficult. Financially, I was lost. We had a small mortgage to pay. I only worked part time in evenings. When Jack was alive, he would come home from work and off I went. He received £20,000 as part of a retirement package from his employers.

Section 6. Treatment/care/support

25. I do not think Jack received any treatment for his infections.

26. No counselling or psychological support was ever made available to Jack or any member of his family in consequence of what happened.

Section 7. Financial Assistance

27. In the 1980's, The MacFarlane Trust paid to me £10,000 but I do not know for what reason. I found out about them from the Haemophilia Society.

28. Two to three years ago, I received a further lump sum of £40,000 but I do not recall who paid that. I was just told by letter that I was entitled to some money. I never made an application for it.

Section 8. Other Issues

29. I have not been involved in any litigation. I have not been involved in any campaigns.

30. When I was first widowed and suffering from the loss of my husband, I would have liked to have more support. But that support never arrived. I was left to fend for myself. I believe those affected should have been sent letters for financial assistance at the time when they had lost a family member. It was left to those affected to make their own enquiries as to whether any payment was due. I had to find money to pay the mortgage, maintain the house, care for the children and pay the bills. The response should have been immediate. For me, the money was not made available when I needed it the most.

Anonymity

31. I do not want to remain anonymous and I am prepared to attend court to give oral evidence to the Inquiry if required.

Statement of Truth

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

Signed...

GRO-C

Margaret Florence Edwards

Date: 17 March 2019