

Witness Name: Louise Edwards

Statement No: WITN0509001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LOUISE EDWARDS

I, Louise Edwards, will say as follows:-

Section 1. Introduction

1. My name is Louise Edwards of GRO-C Leeds, GRO-C I was born on GRO-C 1973. I am unmarried. I have an older brother named David.
2. I make this statement in relation to my late father, Mr Jack Edwards who was born on GRO-C 1938 and passed away on 5 September 1985 aged 47. I was twelve when he died.
3. 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 Infected

4. My father suffered from Severe Haemophilia A. My paternal grandmother was a carrier and haemophilia ran in that side of my family. My uncles John and David both

passed away due to haemophilia. They were not infected with contaminated blood but went through some unfortunate accidents which caused excessive blood loss.

5. As far as I am aware, my father was only ever treated at St James University Hospital in Leeds as this was our nearest haemophilia centre. I recall he was under the care of Dr Swinburn. This is the only doctor I remember treating my father.
6. My father did not know exactly which treatment caused the infection. In the early 1960s my mother told me that my father received Cryoprecipitate. In the mid 1970s, when I was four years old, I saw my mother giving my father a Factor VIII injection. The bottles of Factor VIII were kept in a fridge at home. The Factor VIII kit became a regular part of our lives. My parents collected such treatment from the hospital for home use. I would say my father received Factor VIII a minimum of four times a week. I believe that my father contracted HIV and Hepatitis C as a result of having received contaminated blood during the mid 1970s.
7. I do not know when my father was tested or diagnosed for HIV, (called HTLV3 at the time), or Hepatitis C, which at the time did not have a name. It only came to light after his death that it was in fact Hepatitis C. I do not know which of the two infections came first. My mother informed me that he passed away from AIDS related diseases. I do not know if either or my parents were ever told about his diagnosis but my mother would know if they had been. This is because she attended every appointment with my father.
8. I do not believe that any information was provided to my father in relation to his diagnosis. My mother told me that she was very lucky to have not caught it as she was never told about the risk of her being infected. There was no information provided to her about the risks or any advice given regarding being safe around her husband.
9. My father's death certificate lists Hepatic Cirrhosis as a cause of death.

Section 3. Other Infections

10. As far as I am aware, my father was only infected with Hepatitis C and HIV.

Section 4. Consent

11. To the best of my knowledge, no risks were advised to my father in relation to the Factor VIII products.
12. I do not believe that the hospital tested my father for HIV with his knowledge and consent; however they had established he had the HTLV3 antibodies.
13. I believe the hospital tested my father for Hepatitis as they were aware that he had the infection. I believe that these tests were carried out without his knowledge or consent.
14. I do not know if my father received any direct treatment for HIV or Hepatitis, however I know that in his final two years he frequently went to hospital, often for long periods and was taking around ten to twelve different types of medication, including prednisolone for inflammation and tranexamic acid to help reduce blood loss. I do not know whether any of these were to treat his conditions.
15. I do not think my father was tested for the purposes of research.

Section 5. Impact of the Infection

16. My mother told me that my father seemed at times not to acknowledge or appreciate how bad his illness was and assumed everything would be okay. He chose not to dwell on it. If he did know, maybe he did not want his true feelings to affect his family. My mother knew that he may not make it. She told me that they had plans for household maintenance and refurbishment and she knew he would not be able to see the finished product. He did not allow his conditions to rule his life and carried on as best as he could.
17. In the last six to eight months of his life, my father lost energy. He had so many hospital visits that the staff in the ward all knew him. Physically he lost a lot of weight, but his stomach bulged. In the last holiday photo I noticed that his skin changed colour. He also had what looked like a boil under his eye. He was aware in

the last week of his life how ill he was and around that time he was told that he may not survive. Some years later, upon returning home from school, my mother told me that my father had told her, if the doctors did not treat him, he would return home and take an overdose. My father was not the type of person to say such a thing.

18. He used to work as a factory foreman and was due to take early retirement on medical grounds, but did not get around to it. He was still employed and was off sick when he died.
19. I cannot say for sure if my father was ever treated for his infections therefore I do not know if he encountered any difficulties in obtaining treatment. I do not know if there was any treatment that should have been given to him.
20. I was only twelve when my father passed away. My mother would not allow my father's death to affect my education. We never knew what was wrong with my father. We just knew he was in and out of hospital. His death was caused prematurely. We just got on with our life. I lost my father and nothing could bring him back. My mother made sure we were provided for. Losing a loved one like that without ever knowing that he was dying was very difficult for us. Some people, even to this day, do not know why my father passed away.
21. I was thirteen when I found out by accident that my father had been HIV positive. My mother had an official complaint registered with the hospital in respect of the manner in which the hospital had treated him during his final hospital admittance and his possessions after his death. My father was placed in an isolated side room. On the door, there hung a sign stating 'AIDS Patient' and my mother overheard other patients discussing how "disgusting" it was that my father was allowed in the ward. After his death, his possessions were placed in a plastic bag, had orange cordial poured over them and were handed to my mother. The items within that bag were not in the room or worn by my father in his last days. What is more, the hospital never returned my father's gold signet ring. My mother was informed that the ring was on his body and when the undertaker collected his possessions; my father's body was sealed in a bag due to the infection so it was irretrievable.

22. My mother never informed me about the financial difficulties involved. I don't know how she coped with this and cannot imagine how difficult it must have been for her to lose her husband and raise her children alone

Section 6. Treatment/care/support

23. My parents never received any support. Immediately after my father's death, upon leaving the hospital, my mother was told by a doctor that they didn't want to see her in the A&E because she'd done something "silly" as her husband had just died.

24. My brother and I were never provided with any support. There was no such thing as grief counselling for children. We were told our father died and we got on with our life because we had to.

Section 7. Financial Assistance

25. In 1991, during the first set of legal action, there was a pay-out, but I do not remember who paid or the amount I received. I attended a solicitor's office when I was eighteen to be given a cheque payable to myself. I cannot recall if this was accompanied by a letter. My brother received the same, but again, I do not know the amount.

26. I believe my mother received some money but I do not know of the amount or how much she received.

Section 8. Other Issues

27. My mother was involved in the litigation but I do not know the amount received and I did not know there were any campaign groups out there until last year. This should have never happened in the first place.

Anonymity

28. I do not wish to remain anonymous and I want 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

29th April 2019